



Family Caregiving Project

BEST COPY AVAILABLE

COMPLETED

FAMILY CAREGIVING PROJECT

**A Cluster of Projects Funded by
The Department of Health and Human Services**

**Coordinated by
Office of Human Development Services
June 1987**

THE FAMILY CAREGIVING PROJECT
WORKGROUP PARTICIPANTS
Deborah Bass Chair

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Human Development Services

Deborah Bass, Chair
Executive Secretariat
(202) 245-3176

Cynthia Robinson
Executive Secretariat
245-3176

Nell P. Ryan, Cluster Manager
Office of Policy, Planning and Legislation
245-2874

Bill McPherrin
Office of Public Affairs
245-7110

Jim Steen
Administration on Aging
245-0075

Judy Moore
Administration on Developmental Disabilities
245-1961

Marlys Gustafson
Administration For Children, Youth and Families
755-7758

Health Care Financing Administration

Jean Bainter
Office of Research and Demonstrations
594-7641

Office of the Assistant Secretary for Planning and Evaluation

Floyd Brown
Office of the Deputy Assistant Secretary for Social Services
Policy
245-6443

National Institute on Aging

Kathleen Bond
Older People in Society Behavioral Sciences Research
496-3136

National Institute of Mental Health

Enid Light
Center for Studies for Mental Health of the Aging
443-1185

DEPARTMENT OF LABOR

Jayne Seidman
Ruth Nadel
Women's Bureau
523-6631

VETERANS ADMINISTRATION

Donald Moses
Social Work Department
233-5396

TABLE OF CONTENTS

<u>Organization</u>	<u>Page</u>
Introduction	1
Progress to Date	3
Administration on Developmental Disabilities Projects	4
Administration on Aging Projects	18
Administration on Children, Youth and Families	57
Office of the Assistant Secretary for Planning and Evaluation Projects	65
Health Care Financing Administration Projects	70
National Institute on Aging Projects	78
National Institute of Mental Health Projects	99
Department of Labor Activities	115

9v

INTRODUCTION

Family members are the primary care providers for individuals who require assistance in crisis situations and over the long term. They are the preferred source of care because they can handle "idiosyncratic events" and reach quick decisions about needed care. The dependent person also maintains a greater sense of dignity because the relationship is interdependent, not one-sided.

The need for informal caregivers is growing at a time when the availability of caregivers is decreasing and the responsibilities of caregivers are growing. When the caregivers work and/or have children of their own, or divorce and become single heads of household, their time and ability to provide care is diminished. Adequate support for these caregivers in the form of access to services needed by the functionally impaired relative and self help/support groups or services designed to alleviate caregiver stress can help them meet their own health needs and prevent family breakdown and unnecessary hospitalization or institutionalization.

The Office of Human Development Services (HDS participants include the Office of Policy, Planning and Legislation, the Administration on Aging, the Administration on Developmental Disabilities and the Administration on Children, Youth and Families) has joined with the Office of the Assistant Secretary for Planning and Evaluation, the Health Care Financing Administration, the National Institute on Aging and the National Institute of Mental Health within the Department of Health and Human Services and the Department of Labor and the Veterans Administration to find ways to improve our society's ability to meet the needs of the chronically ill or chronically impaired.

Public funding, historically, has supported services to people who are institutionalized or living in group residential settings to a greater extent than services designed to help people remain in their own homes. The Family Caregiving Project is intended to identify, encourage the development of and disseminate approaches for strengthening the capacity of families to care for functionally impaired relatives and to support families in that role. It is anticipated that, at a minimum this project will:

- o Improve current knowledge about the needs of caregiving families and how those needs can best be made, through discretionary grant awards;
- o Improve predictive tools to assist in the identification of caregiving families at risk of breakdown through discretionary grant awards;

- o Assist in the development of supports for caregiving by stimulating the identification and training of professionals, paraprofessionals and volunteers who are working with caregiving families and testing new approaches such as cooperative exchanges of respite, through discretionary grant awards and work with voluntary agencies;
- o Provide information on how to help the caregiver in need and how to identify them to professionals and paraprofessionals who are working with caregiving families, by disseminating information through service delivery networks, professional and voluntary associations and discretionary grant awards to stimulate state and local dissemination of information;
- o Collaborate with businesses and corporations to develop flexible worksite policies and benefit packages to assist caregivers and increase employee productivity; and
- o Mobilize communities across the country on behalf of caregiving families by encouraging the development an coordination of needed services.

This project also is designed to achieve greater administrative simplicity and coordination among federal agencies and between federal agencies and the voluntary and professional organizations. The administrative goals are to:

- o Provide an opportunity for grantees to share ideas, expertise and findings in order to improve the quality of their projects and increase the impact of project findings;
- o Encourage collaborative activities;
- o Establish a forum for Federal officials, experts and practitioners for discussion of issues of mutual concern;
- o Foster improved dissemination and utilization of project results and determine the need for follow-up activities; and
- o Identify program and policy implications for public and private efforts to support family caregivers.

BEST COPY AVAILABLE

PROGRESS TO DATE

June 1986 Conference

This conference sponsored by the Office of Human Development Services within the Department of Health and Human Services (HHS), brought together 30 grantees funded by a variety of HHS agencies, HHS policy makers, three private foundations, eight national professional and voluntary organizations and many other interested organizations and individuals.

Conference participants identified needed research and activities for the future as well as roles for government and professional/voluntary organizations. Proceedings are available by contacting:

Executive Secretariat
Office of Human Development Services
Department of Health and Human Services
200 Independence Avenue S.W.
Room 322F
Washington D.C. 20201

Special Edition of the Human Development Services News

An area of particular concern to conference participants was the need to disseminate information to caregiving families and to the professionals, paraprofessionals and volunteers who are working with them. Consequently the Family Caregiving Project will be developing shortly a special edition of the Human Development Services News that will highlight innovative projects/grants that are trying to meet the needs of family caregivers in a variety of ways. This publication should be available by Winter of 1988.

Collaborative Work With Professional and Voluntary Organizations

Due to the increasing need for caregivers, support for caregiving families is a high priority topic for many organizations. The Family Caregiving Project has begun to exchange information with professional and voluntary organizations and will develop panels and/or provide materials in the future for conferences sponsored by these organizations.

The remainder of this document describes the purpose of each of the many Department of Health and Human Services grant awards that deal with family caregiving issues and the activities undertaken by the Department of Labor.

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

Administration on Developmental Disabilities

The majority of persons with developmental disabilities under the age of 22 reside at home with their families. Of the estimated 3.9 million persons with developmental disabilities in the United States, only about 145,000 reside in publicly funded Intermediate Care Facilities for the Mentally Retarded. Although most families do decide to keep their relatives at home, they are confronted with enormous burdens that mitigate against that decision. They are faced with chronic stress stemming from such problems as:

- o Social isolation
- o Extraordinary time demands involved with providing care, and teaching adaptive skills
- o Difficulty in undertaking normal family routines that enhance the care provided at home.

In Fiscal Year 1986, ADD awarded grants totaling \$788,029 to demonstrate ways in which policies can be formulated and/or services made available to strengthen the capacity of families to care for their developmentally disabled family member at home, thereby encouraging integration into the community.

In Fiscal Year 1987, proposals were solicited to support demonstrations which address (1) involvement of families in health care, (2) transitions to community living arrangements, (3) community support for families including persons with severely handicapping conditions, and (4) continuum of family support services.

PARENTS REACHING OUT
HDS Project # 90DJ0103

PROJECT SUMMARY

Parents Reaching Out (PRO) is proposing to develop a Family Support Project to provide support services to parents and family members who elect to maintain their developmentally disabled family member at home. Local parent support groups will be expanded and strengthened to serve as the basis for three types of support services.

The first area involves the development and delivery of training in case management and family financial planning. PRO volunteers will work with project staff to develop the training course curriculum. Other volunteers, including local consultants in financial planning, will deliver the training in six regions of the state to at least 120 parents and other family members.

The second area involves connecting families with similar family member disabilities to one another and connecting families to services and resources in their communities. These networking and information services will be developed and implemented in two target zones in the state. This goal includes the development of a family record keeping system to establish linkages.

The third area involves informing parents about the availability of respite care and helping parents organized local in-home respite care opportunities. Descriptions of available respite services will be passed on to parents. Both paid and co-op respite care providers will be recruited in each of the two target zones, and a training session will be developed and delivered in each area.

Material to be developed and disseminated through this project include: trainer and trainee manuals for case management and family financial planning; record keeping systems on family linkages and community resources; trainer and trainee manuals on providing respite care; and program models for local parent networks and respite care co-ops.

PROJECT INVESTIGATOR

Sallie Van Curen
New Mexico Parents Reaching Out
1127 University NE
Albuquerque, New Mexico 87102

PROJECT OFFICER

Judy Moore
(202) 245-1961

PROJECT PERIOD

8-1-86 to 7-31-88

COMMUNITY-BASED RESPITE CARE PROJECT FOR
FAMILIES PROVIDING CARE TO DEVELOPMENTALLY DISABLED
CHILDREN AT HOME
HDS Project #90DD0108

PROJECT SUMMARY

This project demonstrates that combining coordination, referral and parent/provider training in a statewide system of community-based respite care prevents family dissolution and institutionalization of developmentally disabled children, birth to 20. This model, targeted at the 54 percent of Maine families who report that they don't have appropriate respite care, is structured to increase family confidence and competency in caring for the disabled child at home and, thus, relieve stress. Family functioning and community and home-based respite care services will be enhanced, increasing family stability and decreasing institutionalization of disabled children. Two central coordination, referral and training sites for respite care and negotiation of interagency policy and procedures will be established. Joint training modules will be delivered to parents and providers in integrated and funding mechanisms for respite care services and training. The project model will be tested and refined over a three year period. Upon successful completion of the project, its staffing, training and care funding functions will be supported by Maine Department of Mental Health and Mental Retardation. The Department will lend technical assistance to states wishing to replicate the model.

PROJECT INVESTIGATOR

Dr. Robert Durgan
Maine Department of Mental Health and Mental Retardation
State House Station #40
Augusta, Maine 04333

PROJECT OFFICER

Judy Moore
(202) 245-1961

PROJECT PERIOD

9-30-85 to 9-29-88

FAMILY PARTNERSHIP PROGRAM
HDS Project #90DD0124

PROJECT SUMMARY

The Community Service Society of New York proposes a two-year Family Partnership Program to assist 100 South Bronx families with developmentally disabled children to define and obtain comprehensive "packages" of services and informal supports tailored to their needs and reinforcing family-based care. Each family will work in partnership with a Services Guide who will assist in creating the services package, utilizing a voucher mechanism where needed, to arrange services not currently available.

The program will significantly reduce caregiving burdens by improving the flexibility and appropriateness of supports for family-based care. It will build upon three successful CSS programs and will work closely with a variety of other South Bronx programs. The program will include an extensive evaluation to facilitate replication.

Several modular replication materials will be produced: Services Planning Manual, Management Information Systems, Handbook on Voucher Contract Development, Comprehensive Support Planning and Interim and Final Reports.

PROJECT INVESTIGATOR

Dr. Francis G. Caro
Community Service Society
Institute for Social Welfare Research
105 East 22nd Street
New York, NY 10010

PROJECT OFFICER

Kay Smith
Administration on Developmental Disabilities
(202) 245-1961

PROJECT PERIOD

8-1-86 to 7-31-88

PRIVATE SECTOR DISCOUNT TO SUPPORT FAMILIES PROVIDING
IN-HOME CARE TO RELATIVES WITH DEVELOPMENTAL DISABILITIES
HDS Project # 006DD0321

PROJECT SUMMARY

The purpose of the Family Support Discount Program is to increase private sector support to families with developmentally disabled (DD) relatives. The project will develop a network of businesses and professionals to discount goods and services which would otherwise be beyond the family's financial capability. The Family Support Discount Program is patterned after the nationally recognized Senior Citizens Discount Program. Project effort will focus on developing discounts from local businesses, professionals, and from national chain stores. The program's precedent and focus will incur national applicability and replicability.

Project funds will: 1) provide "seed money" to develop a private sector discount network; and 2) provide some initial cash support to families. The project will serve approximately 2,500 DD citizens receiving in-home care in an eight county area of rural Georgia.

Expected project outcomes are: 1) a private sector discount program for DD citizens receiving in-home care; 2) decreased stress in families with DD individuals; 3) decreased out-of-home placements related to financial stress; 4) increased private sector awareness and commitment to the area's DD population; and 5) a model for States to use to supplement systems that support in-home care with private sector participation.

PROJECT INVESTIGATOR

June Di Polito
High Hope Foundation
Route 4, Box 58
Statesboro, GA 30458
(912) 484-8641

PROJECT OFFICER

Manuel Soto
Dallas Regional Office
Regional Program Director
1200 Main Tower
10th Floor
Dallas, Texas 75202
(214) 767-2623

PROJECT PERIOD

9-30-86 to 9-29-89

PROJECT SHaRE (SOURCES OF HELP RECEIVED AND EXCHANGED)
HDS Grant No: 90DD0113

PROJECT SUMMARY

Project SHaRE is a family support project operated by the Family, Infant and Preschool Program at Western Carolina Center, Morgantown, North Carolina. The project is designed to assist families with severely and profoundly developmentally disabled children to maintain their children at home (thus preventing institutionalization) while at the same time insuring the well-being and integrity of all other family members. This is accomplished through the use of the SHaRE organization bartering program that enhances the provision and exchange of services, products, etc. and will lead to self-sufficiency and decreased dependence on public sources of support. The target population of Project SHaRE is 500 rural low Socio-economic status families who have limited physical, instrumental, and emotional support. Support will be provided to these families in exchange for themselves providing a needed product or service to someone else within the SHaRE network. Self-esteem, family integrity, economic self-sufficiency, and related dimension of independence are expected to be enhanced through Project SHaRE efforts.

BRIEF DESCRIPTION OF METHODOLOGY

The primary mechanism for mobilizing family, neighborhood and community support networks is the SHaRE barter exchange program. Project SHaRE members provide to one another, in a reciprocal manner, emotional, physical, instrumental and psychological assistance and help. The barter model used by Project SHaRE is purposively kept simple and uncomplicated in order for members to independently use the system to meet their family needs.

STATUS IN JUNE 1986

Fifty families or individuals currently participate in the project. Twenty of these members are targeted families. The other 30 members include a cross-sectional range of backgrounds, economic levels and skills. In addition, several professionals, businesses, and social service agencies in the community are also providing services and referrals as part of the exchange network.

BEST COPY AVAILABLE

MATERIALS AVAILABLE

The following instruments are available for assessing family needs: family status form; family resource scale; support exchange scale; support function scale; inventory of social support scale; perceptions of control scale; personal well-being index; personal time commitment scale; family inventory of resources; and a parent rating scale.

PROJECT INVESTIGATOR

Caregiver Dunst, Ph.D.
Family, Infant and Preschool Program
300 Enola Road
Morgantown, North Carolina 28655
(704) 433-2661

PROJECT COORDINATOR

Lynda Pletcher, M.Ed.
Project Share
300 Enola Road
Morgantown, North Carolina 28655
(704) 433-2825

PROJECT OFFICER

Mr. Manual Soto
Regional Program Director
Administration for Developmental Disabilities
1200 Main Tower
20th Floor, Room 2000
Dallas, Texas 75202

**SUPPORT FOR FAMILIES THROUGH INTEGRATION OF PERSONS WITH
DEVELOPMENTAL DISABILITIES INTO COMMUNITY RECREATION PROGRAMS
HDS Priority Area No: 1.01**

PROJECT SUMMARY

Families providing care at home for relatives with developmental disabilities may experience a lack of support services necessary to prevent stress and assure a high quality of life for all family members. Access to and skills necessary for meaningful integrated participation in recreation/leisure-time activities by persons with developmental disabilities has been overlooked as a means of providing support for the family. The purpose of this project is to develop, validate and share nationally an innovative approach to supporting families through integration of relatives with developmental disabilities into meaningful recreation activities - the Family Support Through Recreation Model.

The Integrated Recreation Project in cooperation with families, community and human service agencies, and an advisory council will establish guidelines and procedures for: evaluating potential recreation sites; implementing an Individualized Recreation Plan (IRP); training of families, recreation directors, volunteers and participants; evaluation of the effects of these procedures on all parties; and the dissemination of project effects and products on a national level. This project incorporates the cooperative planning necessary to assure continuation locally and the promise of providing a cost-effective model which can be replicated in communities across the United States.

PROJECT INVESTIGATOR

D. Larry Carmichael, Ph.D.
University of Vermont
Center for Developmental Disabilities
444 Waterman Building
Burlington, Vermont 05405
(802) 656-2936

PROJECT OFFICER

Kay Hansford
Administration on Developmental Disabilities
(202) 245-1961

PROJECT PERIOD

8/1/85 - 7/30/88

**COMMUNITY-BASED RESPITE CARE PROJECT FOR FAMILIES PROVIDING
CARE TO DEVELOPMENTALLY DISABLED CHILDREN AT HOME
HDS Priority Area No: 1.01**

PROJECT SUMMARY

This project demonstrates that combining coordination, referral and parent/provider training in a statewide system of community-based respite care prevents family dissolution and institutionalization of developmentally disabled children, birth to 20. This model, targeted at the 54 percent of Maine families who report that they don't have appropriate respite care, is structured to increase family confidence and competency in caring for the disabled child at home and, thus, relieve stress. Family functioning and community and home-based respite care services will be enhanced, increasing family stability and decreasing institutionalization of disabled children. Two central coordination, referral and training sites for respite care and negotiation of interagency policy and procedures will be established. Joint training modules will be delivered to parents and providers in integrated sessions. An Advisory Board will formulate long-range plans and funding mechanisms for respite services and training. The project model will be tested and refined over a three-year period. Upon successful completion of the project, its staffing, training and care-funding functions will be supported by the Department which will lend technical assistance to States wishing to replicate the model.

STATUS IN JUNE 1986

Workplans for each objective have been developed. Project activities are proceeding on schedule. First training session is planned.

INSTRUMENTS/MATERIALS AVAILABLE

Brochure; directory of providers; news release; training curriculum

PROJECT INVESTIGATOR

Dr. Robert Durgan
Maine Department of Mental Health and Mental Retardation
State House Station #40
Augusta, ME 94333
(207) 947-6136

PROJECT OFFICER

Camille Catlett
Administration on Developmental Disabilities
(202) 245-1961

PROJECT PERIOD

9/30/85 - 9/29/88

**FAMILY SUPPORT PROGRAMS FOR THE DEVELOPMENTALLY DISABLED:
A PRIVATE SECTOR APPROACH
HDS Project # 90DD0126**

PROJECT SUMMARY

This project will challenge private corporations, foundations, and the general public to become more directly involved in assisting families with a developmentally disabled member through financial and in-kind contributions. It will strengthen the capacity of families to care for their relatives at home who are at risk of institutionalization and will demonstrate the effectiveness of this innovative approach to funding. It is the first of its type in the nation and will serve as a model which others may use to establish privately funded family support programs. The Community Services Development component will identify and channel private resources to gaps in community family support services and the Family Subsidy component will identify and channel resources to meet the needs of individual families in purchasing services. The project requests HDS funding to provide the initial aid necessary to develop a strong, continuing base of support in the private sector.

PROJECT INVESTIGATOR

Diane Glass
The Community Living Foundation
P.O. Box 3356
Iowa City, Iowa 52244

PROJECT OFFICER

Robert Fain
Kansas City Regional Office
758-5211

PROJECT PERIOD

10-1-86 to 9-30-88

ADMINISTRATION ON AGING PROJECTS

Administration on Aging

Family caregivers provide the primary physical and emotional support for most of the vulnerable older population in this country. The Administration on Aging (AoA) strengthens the efforts of caregivers by assisting its network of State and Area Agencies on Aging to foster the development of family and community-based service systems. AoA also assists by devoting a significant portion of its discretionary funds to building new knowledge and approaches relative to caregiving.

In Fiscal Year 1985, eight projects totalling over \$900,000 were approved to conduct demonstrations in such areas as training and support of caregivers, training and use of volunteers, and improving options for working caregivers. Abstracts for these projects immediately follow this overview.

In Fiscal Year 1986, AoA awarded grants totalling more than \$2.4 million for 22 family caregiving projects. These projects, whose abstracts follow those for the FY 85 projects, fall into three categories:

- 1) demonstration to improve the training and support for family caregivers;
- 2) demonstrations to improve training and information dissemination to those working with family caregivers, e.g. neighbors, volunteers, and service providers; and
- 3) research on various aspects of family caregiving.

All of these projects will actively disseminate information and findings to appropriate national audiences; many will do so through the innovative use of media, e.g. film, video-tape and television.

In Fiscal Year 1987, proposals have been solicited to examine the need for more responsive public and private employer policies for working caregivers. Award decisions on these proposals will be made by (September 1987).

BEST COPY AVAILABLE

STATE-VETERANS ADMINISTRATION(VA):
LONG-TERM HOME CARE FOR MEDICALLY DEPENDENT
FRAIL ELDERLY
HDS Project # 90-AM-0139

PROJECT SUMMARY

Utilizing two sites, Miami (Dade County) and rural Marion-Citrus Counties, this project will offer frail elderly persons a low cost alternative to nursing home care by provision of medical case management through nurses, and caregiver training to enable the frail elderly to remain at home. Further, curriculum development for the furtherance of gerontology training of both HRS and VA staff will be a primary objective of the project. An assessment instrument focused on caregivers will also be produced based on the collective experience of HRS and VA personnel.

The project is an opportunity for the state and the Federal government to demonstrate cooperation in the care management of frail elderly persons. Expected outcomes include: 486 clients served; the provision of caregiver training that is transferable; a well documented case management model; a model services agreement with VA; and medical assessment instruments for caregivers and care recipients. A complete evaluation will be provided utilizing funds from the Robert Wood Johnson Foundation, Inc. and the Veterans Administration.

METHODOLOGY

The project will have two demonstration sites and two control groups. Services will be provided through contractual agreements. Data will be collected through an independent evaluation.

PROJECT INVESTIGATOR

Dawn Pollack
Program Manager
Health and Rehabilitative Services (HRS),
Aging and Adult Services Program, Bldg. 1
1323 Winewood Blvd.
Tallahassee, Florida 32301
(904) 488-2881

PROJECT OFFICER

Howard Wallach
Administration on Aging
(202) 245-0057

PROJECT PERIOD

6/28/85 - 6/27/88

CORPORATE SUPPORT FOR WORKERS WITH FRAIL ELDERLY RELATIVES
HDS Project # 90-AM-0117

PROJECT SUMMARY

The growth of the frail elderly population implies a growth in care demands on their younger relatives, many of whom are working. Current support is offered primarily through the family and the aging network. While corporations are willing to aid workers who have frail parents and relatives, such corporate support is often AD hoc and on a case-by case basis.

The present project is a joint effort of the Center for the Study of Aging at the University of Bridgeport in cooperation with four corporations to improve options for workers with dependent older relatives. The project involves four phases: 1) obtaining base-line data on present patterns of help-seeking by workers with dependent older relatives; 2) establishment of a formal program of response to be made available to workers; 3) establishment and implementation of mutually agreed upon benefits, including short-term worker support groups; and 4) development of crisis-response consultation services. Goals include: 1) expanded knowledge of the caregiving role of workers and its impact on workforce participation; 2) development of corporate awareness of elder care burdens; 3) development of a model corporate support program for elder care providers. Objectives include: 1) the conduct of survey research on elder care burden on workers; 2) a survey of current EAP responses to elder care burdens; and 3) implementation and evaluation of a corporate program of support for such workers.

PROJECT INVESTIGATOR

Michael A. Creedon, DSW, Andrews Professor of Gerontology,
Project Director
Mark A. Edinberg, Ph.D., Director, Center for the Study of Aging
Center for the Study of Aging
170 Lafayette Street
Bridgeport, Connecticut 06601

PROJECT OFFICER

Howard Wallach
Administration on Aging
(202) 245-0057

PROJECT PERIOD

6-28-85 to 8-31-87

BEST COPY AVAILABLE

**ADULT DAY HEALTH SERVICES AS AN EMPLOYEE BENEFIT:
SUPPORTING WORKERS WHO HAVE ELDERLY DEPENDENTS
HDS Project # 90-AM-0158**

PROJECT SUMMARY

This project aims to expand the supports available to workers who are caring for their dependent elderly family members. If workers reduce their level of participation in elder care, the resultant costs could become unmanageable. Because workers can ill afford to abandon either their work or their elders, it is important to demonstrate the feasibility and cost effectiveness of offering employee benefits that support workers who are the primary caregivers for dependent elderly family members.

Employers are generally unaware of the special problems of employees who have elderly dependents as well as the costs they incur when employees miss work or withdraw from employment because of caregiving conflicts. This project will demonstrate that offering these benefits makes good business sense. The specific objectives of the project are to: identify the specific problems which employees encounter in managing the dual roles of worker/caregiver and document associated losses in productivity; identify employee-supported benefits that workers now receive or wish to receive; explore the working caregivers' willingness to co-pay the costs of employee benefits linked to adult day care; obtain estimates of the proportion of employees nationally who have significant caregiving responsibilities for the elderly; demonstrate the costs and benefits of providing adult day care services to elderly parents of a sample of working caregivers; evaluate current tax laws and employment policies to determine the legal and financial feasibility of providing adult day care and other benefits desired by working caregivers; and disseminate project findings through employer education workshops.

PROJECT INVESTIGATOR

Raymond C. Mastalish
National Association of Area Agencies on Aging
600 Maryland Avenue, S.W., Suite 208-W
Washington, D/C/ 200024

PROJECT OFFICER

Howard Waliach
Administration on Aging
(202) 245-0057

PROJECT PERIOD

6-27-85 to 8-31-87

CHARACTERISTICS AND NEEDS OF BLACK CARETAKERS
AND THEIR ELDERLY CLIENTS IN PERSONAL-CARE HOMES
HDS Project # 90-AR-0072

PROJECT SUMMARY

The American Red Cross in cooperation with the Congress of National Black Churches seeks to identify ways of strengthening informal caretakers support of the Black elderly in community-based personal-care homes (private family residences). A study will be undertaken utilizing trained volunteer interviewers in 8 communities. The study has significant implications for research, practice and long-term care policy and the study results will also contribute to the growing body of knowledge regarding the type of support services required by caretakers. The results of the study will provide the foundation for programmatic planning and action through the vast and combined networks of the American Red Cross and the Congress of National Black Churches.

OBJECTIVES

- o To document and analyze the demographic, situational and reported need variables associated with 175 caretakers in personal-care homes;
- o To document and analyze the demographic, functional and health variables of 525 frail black elderly people cared for in personal-care homes; and
- o To identify services of the local Red Cross chapter, the church and other community services that could strengthen the caretaker's role.

PROJECT INVESTIGATOR

Carole Kauffman
American Red Cross, National HDQS.
Emergency & Community Services
17th Street, N.W.
Washington, D.C. 20006

PROJECT OFFICER

Marla Bush
Administration on Aging
(202) 245-0996

PROJECT PERIOD

9-01-85 - 6-30-87

**MEDIA ASSISTANCE TO CAREGIVERS
HDS Project # 90-AM-0222**

PROJECT SUMMARY

There is an absence of audio-visual materials which can be used to start and maintain support groups for caregivers of the impaired elderly. Existing materials leave many important content gaps, are of limited practical value, and are too costly to be affordable and accessible to caregiver groups and individuals. The project is designed to fill this unmet need by producing four 1/2 hour video programs dealing with the following issues: 1) starting a caregiver support group; 2) legal and financial planning for incapacity; 3) coping with caregiving; and 4) alternative placement options.

Each of the programs will be accompanied by a study guide for use in group settings and by caregiving individuals. The study guides will provide guidelines for group discussion, explain complex concepts in greater detail, provide a selected bibliography for further reading, and indicate sources for further information and assistance.

Dissemination is a major component of the project and is built into it from its inception. The tapes and study guides will be distributed at cost to caregiving groups and individuals throughout the country. In addition, the tapes will be of high quality so that they will be acceptable for broadcast by public and cable television.

PROJECT INVESTIGATOR

Ms. Anna H. Zimmer, MSW
Brookdale Center on Aging of Hunter College
425 East 25th Street
New York, N.Y. 10010
(212) 481-4426

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

6-28-85 to 5-31/87

**SENIOR ADVISOR CORPS: A MODEL SUPPORT GROUP FOR PRIMARY
CAREGIVERS OF FRAIL ELDERLY RELATIVES
HDS Project # 90-AM-0123**

PROJECT SUMMARY

Primary caregivers of the frail elderly is the target population for the project. Knowledge, experiences, and methods used in the recruitment, training, and utilization of volunteer retired professionals serving as a model support to primary caregivers will be transferred through the use of audio-visual approaches coordinated with training manuals for national dissemination to primary health care and medical groups serving the frail elderly. National dissemination and utilization of the training materials will be accomplished by contracting with Medical Group Management Association. Founded in 1926, MGMA includes more than 5,000 individual and medical group members in the United States.

OBJECTIVES

- o To strengthen the capability of primary caregivers in their support role to frail elderly relatives
- o To prevent depletion of primary caregiver resources by making available the services of Senior Advisors (volunteer retired professionals)
- o To be responsive to the cross-cultural needs of a diverse ethnic group of primary caregivers through the use of Senior Advisors who are of comparable ethnicity and who have received intercultural training
- o To demonstrate through the use of volunteer retired professionals a cost-effective approach to service delivery.

PROJECT INVESTIGATOR

Oscar Kurren, Ph.D.
The Honolulu Medical Group
Research & Education Foundation
550 South Beretania Street
Honolulu, Hawaii 96813
(808) 537-2211

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

6-28-85 - 9-29-86

ESTABLISHING A NATIONAL NEWSLETTER TO DISSEMINATE
INFORMATION ON SUPPORT FOR FAMILY CAREGIVERS
HDS Project # 90-AM-0118

PROJECT SUMMARY

The purpose of the proposed project is to disseminate information and resource materials for use in enhancing support systems for family caregivers. A newsletter will be established as the medium of knowledge transfer. A newsletter has the advantages of conveying practical information in a manner that is convenient, readable, timely, and cost effective. The target audience will consist of service professionals, agencies, organizations, and community leaders with an interest in assisting family caregivers.

The general outcome of the project will involve the establishment of a network of groups and individuals who have enhanced access to existing resource materials, data, research and evaluation, and best practice techniques. More specific results for the project include: 1) the development of a mailing list of 26,000 organizations, groups, and individuals to receive the newsletter; 2) the production of twelve, 8-page issues containing relevant information concerning resources and training for primary caregivers; 3) the identification of approximately 1,000 groups or individuals who, for a nominal subscription fee, would permit the newsletter to be financially self-sustaining.

PROJECT INVESTIGATOR

Marilynn B. Osterkamp, Ph.D.
Project Director, Principal Investigator
Research Associate
University of Kansas Gerontology Center
Lawrence, Kansas 66045
(913) 864-4130

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

6-28-85 to 8-31-87

FAMILY SERVICE AGENCIES AND
SELF-HELP GROUPS FOR CAREGIVERS FAMILIES OF THE ELDERLY:
A NATIONAL APPROACH
HDS Project # 90-AM-0129

PROJECT SUMMARY

The purpose of this project was to determine how human service agencies can sponsor and/or cooperate with self-help (mutual aid) groups for families stressed by the direct care of the elderly, and to disseminate this information to the field. Results of previous HDS projects were reviewed. Technical assistance through 3 regional group seminars was provided to enable at least 60 other agencies carry out these innovations on an ongoing basis. Finally, the practice technology will be transferred more widely to the human services field through 2000 copies of a published Handbook.

The project is designed to develop a cost-effective new approach to service with caretaker families across the country. Since the aging population in the U.S. is rapidly increasing, and since families are the most common and desirable means to care for most frail elderly, increasing supports for these pressured families can be particularly significant.

PROJECT INVESTIGATOR

Daniel Remine
Project Coordinator
Family Service America
44 East 23rd Street
New York, N.Y. 10001
(212) 967-2740

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

6-28-85 to 12-27-86

**A MODEL DISSEMINATION PROGRAM FOR CAREGIVERS
HDS Project # 90ATO309**

PROJECT SUMMARY

The Connecticut Department on Aging, in cooperation with the Travelers Center on Aging of the University of Connecticut, will develop a model dissemination project to provide information to older caregivers of frail or impaired elderly within the State of Connecticut. The project will allow volunteers in religious groups, social service providers and existing education-support group leaders to establish a unique and cooperative network of both formal and informal support systems.

The goals of the project are to: 1) improve the knowledge of clergy and service providers on elderly and caregiver issues; 2) stimulate the development of educational programs and outreach efforts for caregivers, such as educational-support groups, workshops, symposia, mass media programs, and counseling; and 3) provide relief to older caregivers through mobilizing local community resources.

PROJECT INVESTIGATOR

Lou Goldblatt
175 Main Street
Connecticut State Department on Aging
Hartford, Connecticut 06106
(203) 566-7728

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

9-1-86 to 10-31-87

**RURAL VOLUNTEER INFORMATION PROVIDER PROGRAM
HDS Project # 90AM0231**

PROJECT SUMMARY

A "Rural Volunteer Information Provider Program (VIPPP)" and its instructor and resource manuals- products of a 1984 Discretionary Funds Grant in Missouri - will be replicated in and disseminated to 10 states to meet the informational needs of rural caregivers of frail and impaired elderly, thereby reducing caregiver stress and improving quality of care. Members from 4 major organizations (National Extension Homemaker's Council (NEHC), Cooperative Extension Services (CES), National Association State Units on Aging (NASUA), and National Agencies of Area Agencies on Aging (N4A) will be teamed together on the state and county levels, by being trained as trainers to train members from a nationwide volunteer network, NEHC, as Volunteer Information Providers (VIPs) in 17 rural demonstration counties.

Besides training county teams, the state teams will develop, test, revise, finalize and begin to implement statewide plans to disseminate the VIPPP. Testing of the plans demonstration will not only determine their viability but will also strengthen the functioning of the state teams, thereby enhancing the probability of successful statewide dissemination.

PROJECT INVESTIGATOR

Dr. Burton Halpert
University of Missouri-Kansas City, Center on Aging Studies
Kansas City Missouri 64108-2676
(816) 276-1747

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-1-86 to 1-31-88

INFORMATION DISSEMINATION AND TRAINING FOR
OLDER FAMILY CAREGIVERS AMONG THE RURAL BLACK
ELDERLY IN COASTAL GEORGIA
HDS Project #90AM0241

PROJECT SUMMARY

The family caregivers project seeks to train, and provide elder care service information, and to identify caregivers. Its main objective is to strengthen the family's ability to care for still older family members, neighbors, and friends, among the rural black elderly in Coastal Georgia. Approximately ten neighboring churches in each of three target counties will participate in the proposed project.

Training and information dissemination is the project work of the local network of rural black churches, which historically, have been a "lifeline" for both urban, and especially rural black families. A core group of church volunteers drawn from leadership ranks of each church will assist identified caregivers. Thus, the project seeks to build an elder care service and self-help "infrastructure" to sustain resources for information about up-to-date agency services in the area; 2) a support network of trained individuals who will assist caregivers, and the elderly themselves, in each church.

PROJECT INVESTIGATORS

Ella Hammond Sims
Savannah State College Department of Social Work
Savannah, Georgia 31404
(912) 356-2410

PROJECT OFFICER

Joyce Ella Hammond
Administration on Aging
(202) 245-0055

PROJECT PERIOD

9-1-86 to 1/31/88

BILINGUAL TELEVISION SERIES IN ENGLISH AND SPANISH
WITH CASSETTE COPIES DISSEMINATING INFORMATION TO CAREGIVERS
OF THE ELDERLY
HDS Project # 90AM0246

PROJECT SUMMARY

A twelve part television series for caregivers of the elderly will be produced and broadcast in English and Spanish versions to approximately 2.7 million potential viewers in Southeast Florida. The series, focusing on caregivers of the elderly, will also be available in video cassettes for distribution to community groups, hospitals, libraries, businesses, and individuals in their homes. Elderly volunteers will lead discussions, counsel caregivers and generate public support for the series.

Caregivers need a variety of information; services which provide respite and transportation to enable them to attend support groups where information is shared is often impossible. These 30 minute programs will circumvent the problem by disseminating information in the caregivers' homes and other frequented sites. The programs will be scripted and critiqued by health and gerontological professionals, filmed at a public television station, aired by English and Spanish language stations, and rerun by cable systems in an area that has over 900,000 senior citizens. With minimal editing, these films may be utilized anywhere in the country.

With basic topics such as personal care, utilizing community resources and stress management, the expected outcome is a large audience of older persons more informed as caregivers and better able to maintain frail elders at home.

PROJECT INVESTIGATOR

Howard Russell
Metro Dade County Elderly Services Division
Miami, Florida 33128-1985
(305) 375-5335

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-30-86 to 2-28-88

DISSEMINATION OF INFORMATION TO CAREGIVERS
HDS Project # 90AM0230

PROJECT SUMMARY

Recent efforts to strengthen the informal support system of the frail elderly have met with mixed success. Innovative approaches are needed for the support of, and transfer of information to informal caregivers. The purpose of this project is to develop a model program to serve as the framework for sustaining neighborhood caregiver educational/support groups as a structure for ongoing information dissemination.

The project integrates the most positive aspects of earlier group development efforts, including: 1) techniques for the gradual transfer of leadership to the group's participants; 2) variation of meeting content according to group needs; 3) respite care; 4) a "grass roots neighborhood approach;" 5) "booster workshops" to promote continued participant enthusiasm; and 6) an intergroup information sharing network. The project will incorporate a quasi-experimental test of alternative approaches to extending group longevity.

As a result of project activities, alternative approaches to developing self-sustaining groups will have been tested and the most effective approach identified and documented for replication in other localities.

Products will include: a model program for developing and sustaining educational/support groups for informal caregivers; a pocket guide covering selected caregiver skills in personal care, safety and emergencies; at least 200 informal caregivers will have increased their caregiving knowledge and skills and reduced their levels of stress.

PROJECT INVESTIGATOR

Dr. Theodore Koff
Arizona Long Term Care Gerontology Center
University of Arizona
College of Medicine
1807 East Elm
Tuscon, Arizona 85719
(602) 626-4854

PROJECT OFFICER

Jim Steen

Administration on Aging

(202) 245-0075

PROJECT PERIOD

9-1-86 to 1-31-88

UTILIZING TECHNOLOGY AND A VOLUNTEER NETWORK FOR
STATEWIDE DISSEMINATION OF INFORMATION TO CAREGIVERS
HDS Project # 90AM0244

PROJECT SUMMARY

The College of Education and Behavioral Sciences, Western Kentucky University requests assistance to establish an innovative delivery system that provides information to family, friends and neighbors of the elderly in remote rural sites throughout Kentucky. Multidisciplinary faculty utilizing videotaped programs, teleconferencing and assistance of local volunteers will deliver 100 programs to caregivers of elderly loved ones in 10 rural Area Development Districts. The project tests an innovative information model that could offer cost effective, quality training to caregivers. Key elements are: 1) production of five quality videotapes in identified need areas, 2) installation and operation of a "QUORUM Teleclass," telephone bridge that interconnects multiple rural sites with the University and, 3) statewide network of volunteer training assistants. Unserved needs are met by allowing caregivers to view tapes in a comfortable environment, and to interact with university gerontology experts and other caregivers through follow-up teleconferences at flexible times. Facilitation by local volunteers adapts training to the environment. Once installed, the videotape and teleconference system is an affordable means of impacting care of elderly statewide. An elaborate evaluation design will test the proposed model. Training videotapes and findings on the delivery system will be disseminated regionally and nationally.

PROJECT INVESTIGATOR

Dr. Lois Layne
Western Kentucky University College of Education
Bowling Green, Kentucky 42101
(502) 745-4414

PROJECT OFFICER

Peter Holguin
Administration on Aging
(202) 245-0050

PROJECT PERIOD

9-1-86- to 12-31-87

NOVATIVE APPROACHES TO THE DISSEMINATION OF CAREGIVER
INFORMATION THROUGH ETHNIC AND RELIGIOUS GROUPS
HDS Project # 90AM0225

PROJECT SUMMARY

The Catholic University of America's Center on Aging, its National Catholic School of Social Service and the American Jewish Committee's Institute on Human Relations are conducting this collaborative effort which is aimed at providing needed information to caregivers of the home-bound and frail elderly in a cost effective and easily replicable way. Reaching large numbers of ethnic/religious elderly caregivers not reached before in previous AoA-funded projects, the project targets people whose capacity for self-help will be strengthened by relevant and useful information that will be disseminated to them in 25 planned educational forums in Washington, D.C. and in Chicago, Illinois. Information to be disseminated includes video and written materials. Applicability of the information to the needs of caregivers from many different ethnic/religious and cultural backgrounds will be ascertained. State and Area Agencies on Aging personnel, along with leaders in ethnic/religious communities, will work closely with project staff for a successful dissemination of information to elderly caregivers on both the local and national levels.

PROJECT INVESTIGATOR

Dr. David Guttman
Catholic University of America
National Catholic School of Social Service
Washington, D.C. 20064
(202) 635-5464

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

9-1-86 to 1-31-88

CAREGIVER EDUCATION AND OUTREACH PROJECT FOR
FAMILIES OF THE FRAIL-ELDERLY
HDS Project # 90AM0222

PROJECT SUMMARY

Demographic trends forecast that more and more American families will be asked to provide in-home care for their frail and elderly members. There will be an increasing need for interventions to assist families to meet this challenge.

The Caregiver Education and Outreach Project for families of the at-risk elderly will target strategies to overcome key barriers to service and implement creative programs that meet caregiver needs. The project has national application and is building upon knowledge already gleaned from an extensive and successful experience of serving this population.

OBJECTIVES

- o To establish a caregivers training center
- o To implement an education campaign in the workplace
- o To facilitate the establishment of 20 support groups statewide
- o To extend an innovative caregiver training program into rural areas
- o To produce a videotape on legal/financial planning, a videotape on peer counseling training, a guide for hiring in-home help, a CARES kit for distribution by physicians and hospitals and six fact sheets with coping information.

PROJECT INVESTIGATOR

Mrs. Bobby Heagerty
Good Samaritan Hospital and Medical Center
1015 N.W. 22nd Avenue
Portland, Oregon 97210
(503) 229-7348

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

9-1-86 to 1-31-88

INTERFAITH CAREGIVERS DISSEMINATION PROGRAM
HDS Project # 90AM0224

PROJECT SUMMARY

This project will develop a caregivers dissemination program, based on the work being done presently through a Robert Wood Johnson Foundation grant. Three hundred congregational representatives of different denominations will participate in 20 caregiver programs, in order to reach out to 100 congregations and 3,000 congregational members needing caregiving information, resources, or support. The dissemination program will be evaluated and refined, and a manual will be disseminated nationwide.

The project builds upon the existing Robert Wood Johnson grant in that it places greater emphasis on congregational leaders disseminating information and sustaining caregiver services. If this delegation of responsibility proves successful, large numbers of caregivers can be reached with limited demand on grant funds or professional trainers. This model also builds upon the existing project by extending the program beyond limited sections of Washington, D.C., to the metropolitan Washington area. In addition, a manual will be developed for dissemination around the country, with program replication assisted by interfaith organizations, individual congregations, state and area agencies on aging, provider organizations and gerontology programs at institutes of higher education.

In summary, this caregiver program will be disseminated on a metropolitan basis, evaluated and refined, and compiled into a manual that will be disseminated nationwide.

PROJECT INVESTIGATOR

Mr. Clavin Fields
Institute of Gerontology
University of the District of Columbia
1100 Harvard Street, NW
Washington, D.C. 20009
(202) 727-2778

PROJECT OFFICER

Alice Alderman
Administration on Aging
(202) 245-0975

PROJECT PERIOD

9-1-86 to 1-31-88

ASIAN HUMAN CARE CENTERS - SENIOR EMPOWERMENT PROJECT
HDS Project # 90AM0238

PROJECT SUMMARY

The project is a collaborative effort between the Asian Human Care Centers and community agencies to address the problem of service information deprivation among Asian elderly and their caregivers. The project uses a self-help and self-development approach through the training of bilingual/bicultural volunteers as organizers of information linkages of educational forums in their community. Information on housing, health care, income security, self-help and in-home supportive services will be developed with specific emphasis on the needs of Asian immigrants and refugees. Products of the project include: 1) a filmstrip on the identified areas of needs in English and 7 Asian languages, 2) a study guide, fact sheets, and brochures in eight languages, and 3) a summary final report.

PROJECT INVESTIGATOR

Dr. Carol Iu
Asian Human Care Centers
Synod of S. California and Hawaii
Los Angeles, California 90017

PROJECT OFFICER

Peter Holguin
Administration on Aging
(202) 245-0050

PROJECT PERIOD

9-1-86 to 1-31-88

THE ROLE OF SENIORS AS CONSULTANTS TO CAREGIVERS
OF THE DISABLED ELDERLY
HDS Project # 90AM0237

PROJECT SUMMARY

This statewide project will demonstrate that senior volunteers trained as resource consultants can effectively improve the home-based care of disabled elderly persons through an individualized approach to provide information for caregivers. Working part-time with agencies in rural and urban communities and on Indian Reservations, each resource consultant will make four home visits to identify needs, present relevant information, facilitate referrals, assist in adapting solutions to specific problems, and review these solutions to ascertain if the caregiver was successful in implementing change. Under local agency supervision, with University assistance for special problems, each resource consultant will see 15 caregivers per month. Approximately 14,000 people will benefit from this service including the caregivers, their immediate families and the disabled elderly they serve. A Caregiver Needs Assessment Inventory will be developed for case management and data collection to document changes in caregiver behavior. Specific products include cultural adaptation of health education materials for Native Americans, new information prepared for home-based management of special problems and a project report. Results will be particularly relevant in 1987 when the Nevada State Legislature acts on a long-range community-based health care initiative recently presented by the Governor at his Conference on Aging.

PROJECT INVESTIGATOR

Ms. Betty Dodson
University of Nevada-Reno
Geriatric and Gerontology Center
Reno, Nevada 89557-0046
(702) 784-1689

PROJECT OFFICER

Peter Holguin
Administration on Aging
(202) 245-0050

PROJECT PERIOD

9-1-86 to 1-31-88

ALZHEIMER'S FAMILY SUPPORT GROUP
HDS Project # 90-AR-0077

PROJECT SUMMARY

The Alzheimer's Family Support Group is proposing to establish a tele-communication information network between home-bound caregivers of victims of Alzheimer's Disease and Related Disorders.

The goal of the project is to provide support, information and training to these individuals in a cost effective manner while minimizing the financial and time output of the participants.

The project will conduct twelve presentations/trainings/forums to twenty home-bound elderly caregivers in rural Alaska via Learn Alaska, a tele-communication network. The project also will establish a clearinghouse of information on Alzheimer's Disease and Related Disorders.

The anticipated outcomes for participants of the project include: increased communication; personalized communication; long distance contacts; access to remote resources; decreased isolation; and savings in time and travel costs.

PROJECT INVESTIGATOR

Ms. Rebecca Clement
Alzheimer's Disease Family Support Group
Anchorage, Alaska 99502
(907) 344-3706

PROJECT OFFICER

Alfred P. Duncker
Administration on Aging
(202) 245-0045

PROJECT PERIOD

7-1-86 to 8-31-87

STIMULATING VOLUNTEERISM IN HOUSING FOR THE ELDERLY
HDS Project # 90AM0223

PROJECT SUMMARY

This demonstration is intended to show how, without adding costly formal service programs, volunteers in housing for the elderly can be identified, stimulated and supported to provide needed assistance to their neighbors in various areas of daily living. Results could be used nationally by policy makers and planners to increase the number of people who act on a continual basis as volunteer helpers, aiding their vulnerable fellow residents to remain and participate in the community.

Previous research by the investigators have identified a type of person in housing for the elderly who helps two or more neighbors. The demonstration will be implemented in about 50 facilities in New England. It will involve the screening of all tenants by the building managers using a readily portable, replicable screening checklist developed as part of the demonstration to identify these helpers. They will be supported in a variety of ways, and information provided to them about which of the building tenants need assistance. During an eight-month demonstration period, observation and interviews with the helpers, as well as two follow-up screenings of the total tenant population will yield data about changes in the level of needs of the elderly tenants, and the extent to which these needs are being informally met by volunteer helpers. If these mechanisms are found to be effective in ensuring increased continual volunteer help by elderly tenants to vulnerable fellow residents, such strategies to stimulate a virtually untapped resource would be likely to be adopted nationally by both the public and private sector.

PROJECT INVESTIGATOR

Dr. Claire Gutkin
Department of Social Gerontological Research
Hebrew Rehabilitations Center for the Aged
Boxton, Massachusetts 02131
(617) 325-8000

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-1-86 to 12-31-87

BEST COPY AVAILABLE

VERMONT DISSEMINATION TO CAREGIVERS
HDS Project # 90AM0243

PROJECT SUMMARY

This project utilizes existing models of community education and support services to encourage both families and elder peers to assist dependent older relatives and neighbors.

The project offers two methods of creating a statewide community of support to enable a network of people to face emotionally and physically difficult situations without costly resource diversion. One method develops caregiver support groups. The other establishes peer-to-peer care systems. Both of these components are assisted by a statewide educational program (media and community forums).

PROJECT INVESTIGATOR

Marge Hamrell
Medical Services Division
Vermont Department of Health
Burlington, Vermont 05402
(802) 863-7330

PROJECT OFFICER

Joyce Ella Hammond
Administration on Aging
(202) 245-0055

PROJECT PERIOD

9-1-86 to 1-31-88

UNIVERSITY OF UTAH DISSEMINATION TO CAREGIVERS
HDS Project # 90AM0221

PROJECT SUMMARY

As a function of the increasing numbers of elderly disabled and impaired, the number of caregivers will rise dramatically over the next 20 years. Due to the burden of managing these patients, caregivers experience high levels of stress and strain. This stress can often be debilitating to the caregiver and, in turn, result in the premature institutionalization of the disabled patient. Clearly, an effective intervention package to assist the caregiver in managing the burden and related stress is needed. This need is apparent for both humanistic and economic reasons.

This project will test four intervention approaches to determine the most potent method for reducing caregiver strain. It will serve spouse caregivers of elderly who are identified by physicians as being at risk of institutionalization. Training approaches to be tested include involvement of family members, as well as the primary caregiver in training, and an explicit focus on coping strategies for problem management, as well as techniques employed by existing programs. Franchising will involve distribution of products to human service providers and other interested parties.

PROJECT INVESTIGATOR

Amanda Barusch, Ph.D.
Graduate School of Social Work
University of Utah
Salt Lake City, Utah 84112
(801) 581-4554

PROJECT OFFICER

Joyce Ella Hammond
Administration on Aging
(202) 245-0055

PROJECT PERIOD

9-1-86 to 1-31-88

COMPREHENSIVE EDUCATION PROJECT ON ELDERLY CAREGIVING
FOR OLDER CAREGIVERS AND POTENTIAL HELPING AGENCIES
HDS 90AM0242

PROJECT SUMMARY

The Consumers Union Institute for Consumer Policy Research will implement a multiphased, multimedia effort to increase understanding of the practical and emotional issues of caregiving. Aimed at social service agencies, employers, and caregivers, the model project seeks to help elderly caregivers solve problems. The project will expand and solidify the network of agencies able to disseminate information and respond to caregivers' needs. The Institute will form an advisory committee to assure broad participation and to avoid duplication of effort.

The Institute will hold five training Forums in New York City. The Forums will reach 350 individuals who will pass the information on to 4,200 caregivers.

The Institute will prepare 4000 copies of a "Caregiving Resource Kit" with locally relevant up-to-date materials. Consumers Union will produce a 15-20 minute documentary film/video as a discussion tool. Communities will have access to the kit and the video cassette after the Forums. Tens, possibly hundreds, of thousands will be reached subsequently. Public service announcements on local television will alert the target audience and the general public. A blue-print of the model project will be produced to facilitate duplication.

PROJECT INVESTIGATOR

Ms. Jean Halloran
Institute for Consumer Policy Research
Consumers Union of the United States
Mt. Vernon, New York 10553
(914) 667-9400

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-30-86 to 9-30-87

DEVELOPMENT OF LONG-TERM TRAINING FOR FAMILY AND FRIENDS TO
SERVE AS CAREGIVERS OF ELDERLY INDIVIDUALS SUFFERING FROM
MEMORY IMPAIRMENT, ALZHEIMER'S DISEASE, AND RELATED DISORDERS
HDS Project # 90AM0223

PROJECT SUMMARY

This project builds on a current training grant to help caregivers cope with Alzheimer's patients. It will establish a system for statewide continuing training of in-home caregiver skills for families, friends, and other volunteers of elderly individuals suffering from memory impairment, Alzheimer's Disease, and Related Disorders. The West Virginia Commission on Aging and the state's nine regional Area Agencies on Aging (AAAs) will be directly involved in all phases of the project. A needs assessment will be conducted in each region and three one-day training workshops will be conducted in all nine, primarily rural, regions. AAAs will assist in recruiting caregivers from support groups, churches, Retired Senior Volunteer Program (RSVP), etc., to receive the training. Personnel from AAAs and other social service groups will learn how to provide training locally after completion of the project. Materials already developed by West Virginia University Gerontology Center for Alzheimer's Disease caregivers, including a training manual and an educational slide program, will be revised and utilized. In communities where they are available and willing, caregivers will assist in the training. Evaluations of training sessions will be administered and data collected will be used to improve the training. Materials and procedures developed for this project will be transferable to other rural states.

PROJECT INVESTIGATOR

Ms. Barbara Knight
Gerontology Center
West Virginia University
Morgantown, West Virginia 26506
(304) 293-2081

PROJECT OFFICER

Alfred P. Duncker
Administration on Aging

PROJECT PERIOD

8-1-86 to 12-31-87

MINNESOTA DISSEMINATION TO CAREGIVERS
HDS Project # 90AM0236

PROJECT SUMMARY

The Department of Human Services will replicate and create for franchising a statewide public education program for caregivers called "Caregivers Need Care Too!" This program was developed and implemented in Minnesota last year. It consists of a coordinated media campaign utilizing television, radio and cable systems, followed by printed materials (a series of brochures, poster, bumper stickers, and a workbook for caregivers). The printed materials provide excellent information about caregiving, caregiving support, and the needs of ill and elderly persons to family, friends and neighbors of these persons. A referral system is an integral part of the campaign so that caregivers will have contact with a professional who can provide further information or services.

Expected outcomes include: Maine, Oregon and Missouri will have implemented a coordinated media campaign with training component to reach significant numbers of friends, family and neighbors of ill and elderly citizens; those citizens will have received significant information about how they can be caregivers; and a complete package of media tools and training guides which can be used by any other state or organization in a massive public education of caregivers.

OBJECTIVES

- o To reach 10,000 potential or current caregivers in three replication states
- o To develop in concert with the media campaign a training system to provide information to family, friends and neighbors of ill and elderly
- o To create a franchise package for implementation by other states or organizations

PROJECT INVESTIGATOR

Suzanne Kasper Glass
Department of Human Services
State of Minnesota
St. Paul, Minnesota 55155
(612) 297-1216

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-30-86 to 9-29-87

ASSISTING THE OLDER CAREGIVER THROUGH ADVISORY COUNCIL MEMBERS
HDS Project # 90AM0229

PROJECT SUMMARY

The goal of this project is to improve the quality of care, as well as the quality of life, for both older frail home-bound persons and their older volunteer caregivers. In conjunction with the Close Up Foundation's program for Older Americans, NAAAA will recruit and assist in: 1) The education and motivation of 200 advisory council/board members regarding civic responsibilities relating to health issues and policy for the elderly; and 2) the establishment by advisory councils/boards of Area Agencies of projects designed specifically to assist older persons caring for the frail elderly at home.

Close Up will conduct three one-week sessions focusing on issues related to general government and health care for the elderly in Washington, D.C. for the advisory council members. Resource materials will be produced and distributed to advisory council members for assisting their local advisory councils/boards to work with the staff of the Area Agency on Aging to initiate or enhance programs assisting the older caregiver.

PROJECT INVESTIGATOR

Nancy Gorshe
National Association of Area Agencies on Aging
Washington, D.C. 20024
(202) 484-7520

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-1-87 to 8-31-87

DEVELOPING AND DISSEMINATING CAREGIVER KNOW HOW
HDS Project # 90AM0227

PROJECT SUMMARY

Demographic, financial, and humane considerations dictate that we as a society find improved as well as less costly ways of caring for our frail elderly. Studies during the past decade have called attention to the fact that institutional care cannot be the only answer. Two major initiatives are community based alternatives and care by informal caregivers, i.e. family members and friends. The current project is directly related to improving the ability of family caregivers to provide care.

This project is an innovative, two-pronged approach to the development and dissemination of caregiver know-how in a large metropolitan area. It is a collaborative effort between a long-term care gerontology center, two AAAs and a commercial TV station.

The first program element is a series of monthly public forums to provide practical information to caregivers. For each forum presentation a succinct pamphlet will be produced and distributed.

The second program element is a "Caregiver" segment on a weekly commercial television show, "The Time of Your Life." The "Caregiver" segment will deal with 12 topics addressing specific aspects of the caregiver task. It is anticipated that through these efforts caregiver know-how will be increased, both locally and on a much more widespread basis.

PROJECT INVESTIGATOR

Eric Pfeiffer
Suncoast Gerontology Center
University of South Florida Medical Center
12901 North 30th Street, Box 50
Tampa, Florida 33612

PROJECT OFFICER

Jim Steen
Administration on Aging
(202) 245-0075

PROJECT PERIOD

9-30-86 to 2-28-88

GROSSMONT DISTRICT HOSPITAL DISSEMINATION
OF INFORMATION TO CAREGIVERS
HDS Project # 90AM0252

PROJECT SUMMARY

Grossmont District Hospital will develop and implement a comprehensive education and training program for caregivers in the San Diego area. This program, the Caregiver Education and Training (CET) Project, includes the following components:

- o Two integrated home nursing courses will teach basic home nursing skills to families who plan to care for an ill, frail, impaired or older family member in the home;
- o A companion course will focus on the psychosocial aspects of caregiving and provide information about community resources available; and
- o Short-term follow-up and consultation, either by phone or home visit, will be available to project participants.

The CET Project is designed to impart specific nursing, psychosocial and community knowledge and skills to caregivers, particularly those who are also older adults, who will be caring for a family member in the home. Teaching manuals and instructional videotapes will be developed in consultation with the San Diego Area Agency on Aging and will be available at cost for use in other communities. Data on the caregiving experience of program participants will be collected with specific emphasis on the utilization of skills and knowledge attained from program involvement.

PROJECT INVESTIGATOR

Nancy Byrant
Grossmont District Hospital
La Mesa, California 92041
(619) 465-0711

PROJECT OFFICER

Joyce Ella Hammond
Administration on Aging
(202) 245-0055

PROJECT PERIOD

9-30-86 to 2-28-88

CARE FOR CAREGIVERS PROJECT
HDS Project # 90-AM-0248

PROJECT SUMMARY

The "Care for Caregivers Project" will provide a comprehensive information and support system for elderly family caregivers in Comanche county, Oklahoma. Reinforcing informational programs, respite care will be provided by recruiting respite workers, conducting training and a placement service for in-home respite workers, and providing a respite service away from home. Bi-weekly meetings of a Support Group for Family Caregivers will offer an educational forum as well as opportunity for discussion and sharing.

Conducted through a non-profit gerontology center located on a state university campus, the Project will disseminate information and offer assistance with in-home care of the frail elderly, prevent premature or inappropriate institutionalization of elders, and prevent burnout of caregivers.

Comanche County, a Standard Metropolitan Statistical Area, has 10,000 residents 60 years of age or over, yet it is compact and sufficiently developed in health and social services to offer a good environment for innovative approaches to problem solving in the field of gerontology. The Center for Creative Living Corporation on Cameron University's campus has ample accommodations for meetings, classes, and administration, and maintains close working relationships with the Area Agency on Aging and other health and social agencies in the area.

PROJECT INVESTIGATOR

Julie May
Center for Creative Living
Lawton, Oklahoma 73505
(405) 248-0471

PROJECT OFFICER

Peter Holguin
Administration on Aging
(202) 245-0050

PROJECT PERIOD

9-30-86 to 2-28-87

ADMINISTRATION ON CHILDREN, YOUTH AND FAMILIES

ADMINISTRATION ON CHILDREN, YOUTH AND FAMILIES

Our goals of strengthening family life and enhancing parental capacity to care for children demand new and different forms of assistance and support for parents who are overstressed and temporarily unable to provide appropriate care.

We have solicited in the Fiscal Year 1987 Coordinated Discretionary Funds program two different types of support for such parents: respite care and crisis nurseries.

Respite care is a promising approach to provide short-term relief to persons primarily responsible for the daily care of children who are severely handicapped, chronic or terminally ill, or experiencing severe emotional or behavioral problems.

Crisis nurseries have been recognized as an important resource for parents under stress, in providing a respite to meet a current crisis, as a point for positive contact and involvement with isolated parents, and as a critical community service to prevent child abuse or neglect.

We have funded four applications; two applications in respite care and the others in crisis nurseries. These grants have been transferred to the regional offices to be managed.

SUPPORTIVE RESPITE FOR FAMILIES OF THE
SEVERELY BEHAVIORALLY HANDICAPPED

Project Summary

families of children with severe behavioral disorders needing respite are often denied such services because of the challenging behaviors exhibited by their severely behaviorally handicapped children. Through the provision of supportive behavior management and skills training for respite care providers, the ultimate result of this project is that the family will receive the support necessary to maintain the severely handicapped family member at home. Placement of the client outside of the natural home may be delayed or prevented

The objectives of the project will be accomplished through (1) conducting intensive training for respite providers, (2) development of an Individualized Respite Plan (IRP) for the family, and client, and (3) providing technical assistance as needed throughout the respite period. Major products of this project will include (1) a Final Report, (2) a slide show and/or videotape of the training sequence for use by other agencies, (3) a manual for developing the IRP for use in training respite providers, and (4) a Technical Assistance manual for supervisors. These products will be made available through national, regional, and local groups.

Project Investigator

Ms. Lois Blackwell
314-849-4440
Judevine Center for Austic Children
9455 Rott Road
St. Louis, Missouri 63127

Regional Project Contact Person

Linda Carson
Regional Administrator
816-374-3981

COOPERATIVE RESPITE CARE

Project Summary

The project is designed to provide cooperative respite care services to families of persons with disabilities. The project will also establish and facilitate support groups for parents/caregivers of persons with disabilities and for siblings of persons with disabilities. Currently, respite care services are provided in the catchment area to mentally retarded persons in their homes. This project will expand services to include persons with other disabilities and will provide both home-based and community-based respite care services.

Because such a large portion of the population is military, federally employed or recently relocated, many families are isolated and at risk of increased stress. Due to rapid population growth, support services are not able to keep pace with demand, and in the absence of available support services, friends and extended family, the proposed project will serve to relieve stress and protect the integrity of the family unit.

The expected outcome is the enhance quality of family life among recipient families through the establishment of a support network.

Project Investigator

Ms. Eileen Seal
804-623-1131
Association for Retarded Citizens
314 West Bute Street
Norfolk, Virginia 23510

Regional Project Contact Person

Mr. Rick Spitzborg
Acting Regional Administrator
215-596-0351

AROUND THE CLOCK CRISIS NURSERY

Project Summary

The Crisis Nursery provides 24 hour care for infants and toddlers, birth to 5 years old. Crisis Intervention prevents child abuse and neglect and supports families to encourage self determination. The target populations are teen parents, single parents, and others temporarily unable to provide adequate care, particularly minority and poor families. Twenty-four hour emergency referrals are accepted. Respite care in potential abuse cases is available. In a safe, nurturing environment, children will participate in developmental activities appropriate to their age and designed to provide for physical, emotional, and social needs. The program meets the individual needs of each child; a behavior management plan will be developed by staff and parents. The Child Care Center supports parents through parenting classes, "hands-on" parenting experience under the guidance of trained staff, support groups, and provision of linkage of young people to volunteers who can give on-going support. A handbook will be disseminate to enable replication.

Project Investigator

Ms. Dorthy Critcher
301-685-1460
YWCA of Greater Baltimore
128 West Franklin Street
Baltimore, Maryland 21201

Regional Project Contact Person

Mr. Rick Spitzborg
Acting Regional Administrator
215-596-0351

CRISIS NURSERIES FOR CHILDREN AT RISK**Project Summary**

The Mountain Comprehensive Care Center proposes a collaborative project with the Department for Social Services, cooperation of the schools, and all agencies in the region offering services to children at highest risk of abuse and neglect. The project will identify the highest risk children train staff, educate and support families, and provide temporary child care for the children before abuse occurs. Major outcomes will be to reduce the number of abused and neglected children, and to lower the number of children institutionalized. A final product will be a booklet describing the program outcomes and methodology, especially as it relates to the rural and isolated nature of children and families served.

Project Investigator

Ms. Rita Conley
606-886-8572
Region XI Mental Health and
Mental Retardation Board
18 South Front Avenue
Prestonburg, Kentucky 41653

Regional Project Contact Person

William Behn
Acting Regional Administrator
404-221-2398

STRENGTHENING PARENT/TEACHER SKILLS AND COMMUNITY SUPPORT
FOR HEALTH IMPAIRED CHILDREN IN HEAD START
ACYF No. 90-CD-0507

PROJECT SUMMARY

The Strengthening Parent/Teacher Skills and Community Support project was funded by ACYF under the discretionary grant program. The project demonstrated ways to: (1) increase parent skills and confidence in caring for chronically ill and handicapped children in Head Start program; (2) enable Head Start staff to better prepare children and families for interaction with the health care providers in the community; and (3) to build new community and national alliances among public and private organizations concerned with the welfare of chronically ill and handicapped children. The Association for the Care of Children's Health developed educational materials and pilot tested them in Maryland and Pennsylvania in urban and rural locations. The needs of families coping with caring for children at home and the kinds of support provided by a developmental program such as Head Start were depicted in a training film, Seasons of Caring. The film shows three families with chronically ill children and their interactions with health care providers and early education services. One of the purposes is to help build parents' confidence in the difficult task of providing care, as well as teachers' and administrators' awareness of the stresses the families often face. A third target audience is health care professionals who can learn about the strengths and individual coping styles of families. The need for effective communication and collaboration is an important theme.

METHODOLOGY

During the first year a script for the film and the material for the accompanying study guides were prepared and the material field tested. A play manual for parents of severely handicapped children was produced. Under a no-cost time extension of three months, film revisions were completed and materials printed.

STATUS

The project was completed in June 1986. The film and materials are available from the Association for the Care of Children's Health. They have been well received and the film has been designated as a finalist in the American Film Festival.

BEST COPY AVAILABLE

PROJECT PERIOD

9-84 to 6-86

PROJECT DIRECTOR

Beverly Johnson
Association for the Care of Children's Health
3615 Wisconsin Ave. NW
Wash. D.C. 20016
202/244-1801

PROJECT OFFICER

Jane DeWeerd
ACYF
Box 1182
Wash. D.C. 20013
202/755-7944

**OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING
AND EVALUATION PROJECTS**

AN EVALUATION OF CONSTANT ATTENDANCE ALLOWANCES:
RELATIVE EFFICIENCY AND IMPACT ON INFORMAL CAREGIVERS
ASPE Priority Topic #A-2

PROJECT SUMMARY

This research project measures the extent to which there are cost-savings associated with substituting constant attendance allowances for other forms of public support for non-institutional long-term care, particularly home care, for dependent persons and frail elderly with similar needs, dependencies and other characteristics. The study compares health care and long-term care utilization of persons receiving an attendance allowance or home care, controlling for a set of important personal characteristics which might also affect services utilization. The project also measures the relative impact of these interventions on the substitution of public resources for private effort spent on behalf of dependent persons. A sample of 139 beneficiaries was drawn from the case loads of the Veterans Administration House-bound and Aid and Attendance Allowance programs. These beneficiaries received a functional assessment and were interviewed for important socio-economic, demographic, and services utilization data for the previous 12 months. These data are combined with comparable data on persons interviewed through the Long-Term Care Survey (DHHS) to form the basis of multivariate statistical analysis.

METHODOLOGY/PROGRAM STATUS

The study's VA sample population was limited to persons age 65 or over who were receiving AA/HB benefits under the non-service connected pension program. The population served by this means-tested program has income and disability characteristics similar to that of the potential target group: low-income disabled elderly. Cluster and stratified techniques were used in sampling this population which permitted more efficient data collection efforts. These sampling techniques have unavoidable negative implications for the generalizability of the study; nevertheless, the study does inform policy in the care of the aged.

The VA study group consists of those persons who responded to the original request for study participation, did not live in a nursing or other extended care home, and were able to be contacted (by phone or visit) to arrange for an interview. The beneficiary survey for the VA study instrument was developed using selected questions from the Long-term Care Survey. This approach maximized the comparability between the study and control groups, and reduced the cost of the study by obviating the development of a new survey instrument for the study. Additional questions pertaining specifically to the VA program were included in the VA survey, however.

The sample of 139 beneficiaries from the Veterans Administration House-bound and Aid and Attendance Allowance programs is being compared with two subgroups from the Long-term Care Survey: 1) persons who met VA sample selection criteria and who received formal care from a helping organization.

The first task of the analysis was to assess if and to what extent the groups differ with respect to personal characteristics which might affect the use of health care or help at home with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) needs. These important differences have been identified by the calculation of means and frequency distributions for each group, which have been compared using Student t and chi-square statistics. Differences between the groups identified in this phase of the analysis are being controlled for in current analyses of health care and home help use with multivariate statistical methods, including multiple regression.

PROJECT INVESTIGATOR

John M. Grana, Ph.D.
Project HOPE
Center for Health Affairs
Carter Hall
Millwood, Virginia 22646
(703) 837-2100

PROJECT OFFICER

Floyd Brown
Office of The Assistant Secretary for
Planning and Evaluation
(202) 245-6443

PROJECT PERIOD

9/28/84 - 1/31/86

**SUSTAINING FAMILY CAREGIVING OF THE ELDERLY: HOUSING,
FAMILY SUPPORT AND THE DEMAND FOR INSTITUTIONAL CARE**

PROJECT SUMMARY

This project will examine how housing or other contextual attributes facilitate family caregiving to the elderly, thereby lowering the demand for institutional care. The practical importance of this topic is that if housing features are facilitators of family caregiving which, in turn, lowers the risk of entering an institution, then policy decisions that increase the accessibility of such housing features can strengthen these natural family support systems in a non-intrusive way, while also reducing institutionalization.

The data base for the study will be the Long-Term Care (LTC) survey, collected in 1982 by the Bureau of the Census for DHHS. The data analysis will be divided into three phases. First, appropriate single-dimensional and multi-dimensional scales and indices of key domains (e.g. health and functional status, family support, service use, etc) will be constructed. Second, the relationship between housing circumstances and risk of institutionalization will be explored for various subgroups of the sample. Third, different conceptualizations of how housing attributes may influence the risk of institutionalization will be tested. The practical applications of findings from the analysis will be fully considered from the perspectives of administrative feasibility, effectiveness, and cost efficiency.

METHODOLOGY

Path analysis, a multivariate modeling technique, will be used to explore these questions. Two national data bases - the 1982 Long-Term Care Survey and the 1978 National Annual Housing Survey - are being statistically matched to form a rich set of measures of multiple domains including functional impairments, family support, service utilization, and housing attributes.

STATUS

In the last phase of data base construction.

PROJECT INVESTIGATOR

Robert McKittrick
The Urban Institute
2100 M Street, N.W.
Washington, D.C. 20037
(202) 857-8710

PROJECT OFFICER

**Paul Gayer
Office of the Assistant Secretary
for Planning and Evaluation
(202) 245-6613**

HEALTH CARE FINANCING ADMINISTRATION

HCFA/ORD Mission

The health Care Financing Administration (HCFA), which is responsible for the Medicare program, Federal participation in the Medicaid program, and related health care quality assurance programs, was established to combine these programs in a single agency. Within HCFA, the Office of Research and Demonstrations (ORD) provides leadership and direction for demonstrations, evaluations, research and analytical studies that relate to these HCFA programs.

EFFECTS OF ALTERNATIVE FAMILY SUPPORT STRATEGIES
HCFA No. 95-C-98281/0-03

PROJECT SUMMARY

The objective of the project is to determine the effects of three types of family support programs. Using an experimental design the project assesses the impact of family support programs which (1) provide respite services; (2) provide family training and education; and (3) provide training in conjunction with respite services. More specifically the aims of this project are:

- 1) To determine whether the provision of respite services, family training, or the two combined will affect the level of family burden, the length of time families continue caring for their elderly members and ultimately the cost of long term care for dependent family members.
- 2) To determine whether the effects of any of the three types of support strategies are significantly different from one another.
- 3) To determine whether family characteristics or individual characteristics alter the impact of the three types of family support programs.
- 4) To determine whether families and elderly have preferences for different types of services within the three types of family support programs. That is, to determine which type of respite services families prefer and which type of family training program families prefer to use more often.

METHODOLOGY

A total of 541 family units were studied through interviews. Subjects include 576 elderly individuals who presented themselves to an agency offering support services. For each elderly subject at least one relative who has been designated as a caregiver was also included in the study. The family units were assigned to one of five treatment groups or a control group. Key outcome variables that are being measured include: family burden; the length of time family members continue to serve as primary caregivers; the propensity toward institutionalization; and the cost of long term care support services. Data will be collected at four times during the study. The elderly subjects are interviewed before and after 12 months of intervention services. Family members are interviewed a total of four times.

STATUS

All service delivery and participant interviewing has been completed. The staff are performing data analyses and final report preparation. The project ends May 31, 1987 and the final report is due within 90 days of that date.

MATERIALS AND INSTRUMENTS AVAILABLE

Materials developed for the seminars have been completed and are currently being published by the University of Washington Press. For more information about this material, you may contact Ms. Juanita Pike at (206) 543-4050. The materials have also been made available to the public as a technical assistance document published by the Administration on Aging.

PROJECT PERIOD

5/85-5/87

PROJECT INVESTIGATOR

Rhonda J. V. Montgomery, Ph.D.
Institute on Gerontology
Wayne State University
71-C East Ferry
Detroit, Michigan 48202
(313) 577-2304

PROJECT OFFICER

Ms. Dana Burley
Division of Long Term Care
Experimentation
Office of Research and Demonstrations
Health Care Financing Administration
2-F-6 Oak Meadows Building
6325 Security Boulevard
Baltimore, Maryland 21207
(301) 594-7649

RESPITE CARE CO-OP FOR IMPAIRED ELDERLY
HCFA No: 18-P-98398/5-03
Co-Funded With HDS (AoA)

PROJECT DESCRIPTION

Elder Care Share is a respite care exchange program which is designed to provide unlimited low-cost quality respite care to family caregivers, to prevent exhaustion, and ultimately, to prevent unnecessary institutionalization of the elderly impaired. Included in the design is the intent to strengthen the existing natural family support system and to develop peer group support for primary caregivers of older persons. An additional objective of the project is to disseminate information on the co-op model to potential developers.

METHODOLOGY

Elder Care Share members train each other to care for their frail elders, and exchange care among themselves as a means of providing relief from constant care. Member families operate a care exchange in which care received is paid for by care given. There is no exchange of money. In addition the members meet regularly to exchange information and provide mutual support. All of the co-op activities are facilitated by a professional coordinator.

Dissemination workshops for prospective developers were held at five locations in Michigan. An assessment of the impact of both the model co-op and the dissemination workshops was carried out by an outside contractor.

STATUS

A model co-op program has been established in Kalamazoo, Michigan with eleven member families currently exchanging care, and meeting monthly for mutual support and information. A second co-op in a neighboring county is being developed. The South central Michigan Commission of Aging succeeded in obtaining local funding to support the program for the year following completion of the grant period.

INSTRUMENTS/MATERIALS AVAILABLE

Policy and Procedures Manual, Handbook and Care Folder Forms
Slide Tape Show #1 - Description of Elder Care Share
Slide Tape Show #2 - Development of Elder Care Share

PROJECT PERIOD

9/83-12/86

PROJECT DIRECTOR

Ms. Irene Loss
South central Michigan
Commission on Aging
8135 Cox's Drive
Portage, Michigan 49002
(616) 327-4321

PROJECT OFFICER

Ms. Jean L. Bainter
Health Care Financing
Administration
2F51 Oak Meadows Building
Security Boulevard
Baltimore, Maryland 21207
(301) 594-7641

A VOUCHER INSURANCE PLAN TO MOBILIZE INFORMAL SUPPORT
AMONG THE ELDERLY: PHASE II
HCFA Project 500-84-0064

PROJECT SUMMARY

The Voucher Insurance Plan (VIP) was funded by HCFA under the Small Business Innovation Research Program (P.L.97-219). The project, which developed an exchange system to mobilize formal caregiving among the elderly, was tested in a senior center in California. For each hour of household and personal care services provided by a volunteer, a voucher is earned which the volunteer can redeem later for similar services. Results from Phase I indicate that a significant number of seniors are interested in joining the VIP that they were interested in receiving and providing a wide range of household and personal tasks; and that they prefer to be served by and serve other plan members with specific demographic and social characteristics. During Phase II, the VIP was implemented, tested, and refined. By the end of the project, three products were developed: user-friendly micro-computer software to facilitate matching volunteers with recipients, and maintaining member accounts; a "How to Operate a VIP: manual to set up and run a VIP; and a brochure to promote the VIP among prospective members and voluntary associations, such as senior center, churches, and trade unions. These products are expected to minimize the administrative costs of establishing future VIP's.

METHODOLOGY

During a 15 month demonstration period, the VIP developed and tested administrative tools to facilitate the exchange of services and the maintenance of records, materials, and procedures to recruit members; and record patterns of participation.

STATUS

The project was completed in December 1986. The original VIP is continuing with non-Federal funding. The reports and products of this project can be obtained from the Berkeley Planning Associates at their address below.

PROJECT PERIOD

9-85-12/86

PROJECT INVESTIGATOR

Stuart P. Hanson
Berkeley Planning Associates
3200 Adeline Street
Berkeley, California 94703
(415) 652-0999

PROJECT OFFICER

David Schwartz
Health Care Financing Administration, ORD
P.O. Box 11972
Baltimore, Maryland 21207
(301) 594-8147

NATIONAL INSTITUTE ON AGING PROJECTS

RESEARCH ON FAMILY CAREGIVING
AT THE NATIONAL INSTITUTE ON AGING

Research on family caregiving is an becoming an important component of the NIA Behavioral and Social Research (BSR) program which supports research on social and behavioral factors that affect both the process of growing old and the place of older people in society. Most research on family caregiving falls within the Social Science Research on Aging (SSR) component of the program, one of three subunits. (The other two components of the BSR program are Adult Psychological Development (ADP) and Demography and Population Epidemiology (DPE). SSR is concerned with the relationships of older people to the various social institutions in which their lives are embedded such as families, households, and communities; work and educational organizations; and health care systems including nursing homes; and with how social and environmental processes, interacting with biological processes, influence health and physical functioning in the middle and later years.

It is well established that the family is the older person's main source of affection, emotional support, and care, but also that the family is undergoing many changes: increasing longevity has revolutionized the family so that four, even five, generations of a family are alive at the same time. Divorce and remarriage, growing labor force participation by women, and the decline in family size are affecting the family system. The diversity of the population requires that research consider family patterns in different population subgroups--Blacks, Hispanics, Asian Americans, Native Americans, rural populations, and so on. NIA-supported studies are investigating the nature of family relationships in the middle and later years, changes in multigenerational family composition and living arrangements including changes associated with divorce and remarriage, family relationships and health, as well as the care of older relatives by family members. Studies on family caregiving are addressing caregiving for frail elderly generally as well as for patients with Alzheimer Disease, stroke, coronary conditions, and others. Other studies are concerned with means of training caregivers and reducing stress and burden associated with caregiving.

Information about NIA research programs may be obtained by writing or calling:

Behavioral and Social Research
National Institute on Aging
Building 31 - Room 4C32
Bethesda, MD 20892
(301) 496-3136

FACTORS DEFINING CAREGIVERS
NIA GRANT NO. 1 R01 AG05702-01A1

PROJECT SUMMARY

This project is investigating the factors related to the assumption of the caregiving role by family members. Families of community dwelling elderly persons needing assistance will be compared with a matched sample of families in which the elderly person resides in an institution. Data is being collected on demographic characteristics, family and household structure, health status of each family member, morale, attitudes of affection and obligation, level of objective and subjective burden, types of tasks performed, length of time in role of primary caregiver.

PROJECT INVESTIGATOR

Dr. Edgar F. Borgatta
Institute on Aging
University of Washington
Seattle, Washington 98195

PROJECT OFFICER

Kathleen Bond
Behavioral and Social Research
National Institute on Aging
(301) 496-3136

PROJECT PERIOD

8/1/86 - 1/31/89

RESPITE CARE FOR OLDER ADULTS - A PROTOTYPE
NIA GRANT NO. 1 R43 AG05464-01

PROJECT SUMMARY

The purpose of the project is to establish and evaluate a model of respite service provision to frail older adults using a foster care model. The research goal is to establish a prototype within the private business sector for overnight respite. Dependent older adults (55 years and over) will be placed in private residences for overnight stays of up to six weeks. Screening and training materials will be developed. The project will also develop a financial database, licensure recommendations, and evaluate the effect of this service on feelings of burden and stress in caregivers and the functional and mental status of the frail older adults.

The first phase of this Small Business Innovative Research Award has been completed. In Phase I, the project established preliminary data on the clients referral market and obtained and trained fifteen care providers. In Phase II, the project will recruit and train care providers extensively, solicit clients, and develop licensure requirement recommendations.

METHODOLOGY

To evaluate the functional and mental status of the older adults and feelings of burden and stress in caregivers, a quasi-experimental design with follow-up will be used. Subjects will be evaluated before and at four time intervals after to assess changes in feelings of burden and stress and functional and mental status as well as living arrangements. Analysis will utilize Anova, Manova, Logit and Probit. Financial data will be generated using standard accounting procedures.

MATERIALS AVAILABLE

Program Brochure

PROJECT INVESTIGATOR

Joan Brogdan
Kin Care
3003 N. Racine
Chicago, Illinois 60657
(312) 929-6033

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Older People in Society Behavioral Sciences Research
(301) 496-3136

PROJECT PERIOD

7/1/87 - 6/30/89

ENHANCING CAREGIVERS' CAPACITY TO CARE FOR FRAIL ELDERLY
NIA Grant No. R01 AG04572-02

PROJECT SUMMARY

This project is testing two strategies for enhancing the capacity of relatives to care for frail elderly, comparing skill training, classes and information/support classes with "treatment as usual" (inpatient respite, outpatient respite or geriatric day care). The project will evaluate two different psycho-educational programs (compared to a treatment-as-usual control condition) for their effectiveness in relieving caregiver stress, burden, and depression.

METHODOLOGY

Caregivers are recruited from three types of respite programs: overnight respite, day health, and day care. After screening, they are randomly assigned to either of the active interventions (classes to Improve Life Satisfaction or to improve Problem-Solving Skills) or to the treatment-as-usual condition. All participants are assessed after 3 months (when interventions conclude) and again at 3 months, 6 months, and 1 year post-treatment. Those in the delayed treatment condition are given the opportunity to participate in one of the class series when the next "round" is offered at their respite center.

STATUS

This project began its third year. Considerable time was spent developing and pilot-testing a variety of measures and writing the manuals for each of the interventions. Approximately 125 caregivers had enrolled to date, and another 125 were anticipated before the project is completed. Preliminary results indicate that both interventions are helpful and that change in self-efficacy is significantly related to reduction of caregiver distress.

INSTRUMENTS/MATERIALS AVAILABLE

Self-efficacy and problem-solving measures were developed for this study and are available, as are instructor's manuals for each of the two types of classes. In addition, information as to the reliability of several commonly used caregiver measures is also available.

PROJECT INVESTIGATOR

Delores E. Gallagher
VA Medical Center
3801 Miranda Avenue
Palo Alto, CA 94304
(415) 858-3989

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Older People in Society Behavioral Sciences Research
(301) 496-3136

PROJECT PERIOD

4/01/84 - 3/31/89

HOME-BASED BEHAVIORAL TREATMENT OF THE ELDERLY
NIA GRANT NO. R01 AG02612-03

PROJECT SUMMARY

This research was designed to develop and evaluate the effectiveness of a home-based behavioral family intervention program. The goals of the project were to achieve optimal long-term functioning of elderly persons with increasing mental health needs with related excess disabilities associated with the problems of old age. An assumption of this research was that the elderly person's behavioral excesses and deficits are partially maintained through interaction between them and the supporting persons. Therefore, caregivers, including spouses, children and friends, were trained to use behavioral management procedures, especially those involving reinforcement and stimulus control techniques. In addition, community services were included when needed and available. Sixty-six client caregivers were included in the program and an additional 12 were included in a caregiver group training developmental effort.

METHODOLOGY

The primary data source for this research included behavioral data using single-case designs to evaluate interventions in individual cases. These data are combined with the OARS, MSQ, Zarit Burden Scale, and administered pre and post intervention, to evaluate the project. Non-standardized consumer evaluations and follow-up questionnaires were used to evaluate consumer satisfaction and changes in living situations of the elder client.

STATUS

This program was completed and the results are being generalized to a project combining adult day care and caregiver training: "Analysis of Behavioral Programming for Alzheimer's and Other Dementia Clients" funded by the Administration on Aging.

INSTRUMENTS/MATERIALS AVAILABLE

A number of individual instruments and detailed intervention outlines are available in the book, Care of the Elderly: A Family Approachable (1984) New York: Pergamon Press. Other individual assessment tools are available directly from the Project Director.

PROJECT INVESTIGATOR

Elsie M. Pinkston, Ph.D.
The Elderly Support Project
969 East 60th Street
Chicago, Illinois 60637
(312) 962-1176

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Behavioral and Social Research
(301) 496-3136

PROJECT PERIOD

5/84 - 9/85

EMPLOYED DAUGHTERS, FAMILY SYSTEMS, AND OLD PARENTS
NIA GRANT NO, R01 AG03484-02

PROJECT SUMMARY

This project investigates the effects of women's labor force involvement, which continues to increase, on the ability of families to care for the aged. Qualitative data from pairs of daughters of older parents finds that the siblings usually do not name one or the other as primary caregiver. Rather, arrangements considered equitable were negotiated among siblings. If two daughters are potentially available, the fact that one is employed outside the home does not "excuse" her.

METHODOLOGY

Fifty pairs of sisters with different employment statuses who had parent or parents aged 75+ completed a questionnaire about members of their families including parents(s), sibling(s), and in-laws. Each sister was then interviewed using open-ended questions to discover how she and her siblings were involved in providing services to her old parent(s). They were analyzed using qualitative and quantitative methods.

STATUS

The project ended officially March 31, 1986. Papers presented at professional meetings are being prepared for submission to journals. The papers include one in which the effects of employment status are examined; one in which the relationship between family variables and both the division of responsibility and perceived adequacy of care are examined; and two in which the division of labor among siblings is examined. One additional paper was inspired by, but does not draw directly upon, the data collected for this project.

INSTRUMENTS/MATERIALS

The questionnaires used in the project are available upon request. In addition, the papers presented at professional meeting are available request.

PROJECT INVESTIGATOR

Sarah H. Matthews
Department of Sociology
Case Western Reserve University
Cleveland, Ohio 44106
(216) 368-2698

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Older People in Society Behavioral
Sciences Research
(301) 496-3136

PROJECT PERIOD

9/83 - 3/86

SOCIAL NETWORKS AND THE CARE OF FRAIL ELDER
NIA GRANT NO. 5 R01 AG03869-02

PROJECT SUMMARY

This community survey is attempting to identify specific network dimensions that influence the degree of care provided by the informal Caregiver; the relationship between characteristics of the informal network and the use of formal services; and the variables, degree of frailty, perceived health status, and geographic location residence.

METHODOLOGY

Cross-sectional survey of a linked sample of randomly selected, community-based frail elders (n=635) and their primary informal caregivers (n=429). Using a mixed-mode approach, the field design involved three distinct stages of data collection: 1) next line mailed screening of random sample (n=5855) of elders; 2) telephone interviews with eligible frail elders; and 3) next line telephone interviews with primary caregivers of these elders.

STATUS

Completed.

INSTRUMENTS AVAILABLE

Screening index, interview schedules for frail elders and caregivers Final Report

PROJECT INVESTIGATOR

John B. McKinlay
Boston University
96-100 Cummington Street
Boston, MA 02215
(617) 353-9395

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Behavioral and Social Research
(301) 496-3136

PROJECT PERIOD

9/83 - 2/86

CHANGES CAUSED BY DISABLING STROKE
NIA GRANT NO. 5 R01 AG04349-03

PROJECT SUMMARY

The objectives of this project are to investigate the impact of a first stroke on the social networks of primary caregivers and stroke patients in the first year following the stroke, and to examine changes over three years in depression and psychological well-being among caregivers and patients.

METHODOLOGY

The study design is longitudinal. Caregiver and stroke patient dyads are interviewed at three points in time: within 3 to 8 weeks of the stroke, six months after the first interview, and one year after the initial interview.

STATUS

Three hundred victims of disabling stroke were being followed in the study. The final wave of data collection was to be completed in August 1986. Attrition has been about 15%.

INSTRUMENTS/MATERIALS AVAILABLE

An extensive survey instrument was developed and pretested for this study. The instrument provides detailed information on social networks, functional status of stroke patients, well-being of stroke patients and caregivers, and perceived burden, as well as relevant demographic and health variables.

PROJECT INVESTIGATOR

Richard Schulz, Ph.D.
1617-E Cathedral of Learning
University of Pittsburgh
Pittsburgh, PA 15260
(412) 624-2311

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Behavioral and Social Research
(301) 496-3136

PROJECT PERIOD

9/84 - 8/85

STRESS IN ALZHEIMER PATIENT-SPOUSE INTERACTIONS
NIA GRANT NO. R01 AG06770-01

This project examines the interrelationship between cognitive and behavioral deterioration in Alzheimer's Disease patients and psychological stress in the spouse. Analysis of data from 90 couples will be based on a theoretical model which involves stressors, resources, vulnerability, and distress.

PROJECT INVESTIGATOR

Dr. Peter P. Vitaliano
Department of Psychiatry and Behavioral Sciences
University of Washington
Seattle, WA 98195

PROJECT OFFICER

Kathleen Bond
Behavioral and Social Research
National Institute on Aging
(301) 496-3136

PROJECT PERIOD

7/1/86 - 6/30/89

PARENT CARING AND THE MOTHER-DAUGHTER RELATIONSHIP
NIA GRANT NO. 1 R01 AG05155-01A1

PROJECT SUMMARY

This is a longitudinal study to investigate the effects of parent-caring on the quality of the mother-daughter relationship during middle age. Dependent, unmarried elderly women residing with or near a daughter who is the primary caregiver will be compared with non-dependent elderly women living in similar situations. Measures will assess perception of the reactions to the caregiving situations, perceived costs and benefits of parent-caring, and perceived relationship quality.

PROJECT INVESTIGATOR

Dr. Alexis J. Walker
Department of Human Development
and Family Studies
Oregon State University
Corvallis, OR 97331

PROJECT OFFICER

Kathleen Bond
Behavioral and Social Research
National Institute on Aging
(301) 496-3136

PROJECT PERIOD

6/1/86 - 5/31/88

ADULTS CHILD CARETAKERS OF DEPENDENT PARENTS
NIA GRANT NO. AG05150-01A1

PROJECT SUMMARY

This is a study of adult children's reactions to their elderly parents' needs for aid and support. It will examine the stresses and strains imposed by the presence of a parent with Alzheimer's Disease, the effect of these stresses and strains on family process, factors which mediate this effect, and how adult children and their parent attempt to resolve problems. Interviews are being conducted with families consisting of one dependent parent and two siblings per family. The spouse of each sibling will also be administered and abbreviated interview questionnaire.

PROJECT INVESTIGATOR

Dr. Phillip G. Weiler
Department of Community Health
School of Medicine
University of California
Davis, California 95616

PROJECT OFFICER

Kathleen Bond
Behavioral and Social Research
National Institute on Aging
(301) 496-3136

PROJECT PERIOD

12/01/85 - 11/30/88

MENTAL HEALTH, ADAPTATION, AND CARETAKING OF THE AGED ILL
NIA GRANT NO. 1 R01 AG05248-01

PROJECT SUMMARY

Elderly heart attack patients and their primary caregivers are being studied in the early post-hospital stage of recovery to determine the progress and problems of both. Researchers are investigating the effects of biomedical, social and psychological resources on the patient and caregiver. Care of the recovering heart patient is difficult and early results from this longitudinal study indicate that the older patients and their older caregivers experience several adverse effects. Resources are hypothesized as ameliorating the negative effects among caregivers, as well as patients.

METHODOLOGY

A longitudinal, two wave study of 200 elderly heart patients and their 200 primary caregivers is being undertaken in the Detroit metropolitan area. Six week post-hospital interviews and one year follow ups will constitute the two panels.

STATUS

All 400 persons (patients and caregivers) had been interviewed once. Data were being analyzed. The second wave was beginning. Results of short term effects are available. Long-term findings will be available by the end of 1987.

INSTRUMENTS/MATERIALS AVAILABLE

An extensive questionnaire with demographic, health, stress, coping, mental health, social support, and caregiving strain items was developed for this study. It is available for reference or use by other researchers. Materials summarizing the early data analysis are also available, as is the Progress Report submitted to NIA, summarizing findings among 1/2 of the sample.

PROJECT INVESTIGATOR

Rosalie F. Young, Ph.D.
Department of Community Medicine
Wayne State University
540 E. Canfield
Detroit, MI 48201
(313) 577-1033

PROJECT OFFICER

Kathleen Bond
National Institute on Aging
Older People in Society Behavioral Sciences Research
(301) 496-3136

PROJECT OFFICER

12/01/84 - 11/30/87

CAREGIVER RESPONSES TO MANAGING ELDERLY PATIENTS AT HOME
NIA GRANT NO. 1 R01 AG06584-01

PROJECT SUMMARY

This is a longitudinal study of factors influencing home health care of chronically ill elderly from a sample of older patients being served by home health care agencies. The project is examining how family caregivers' level of involvement in care and their perceived burdens are associated with patients' limitations in physical activity and mental states, duration of caregiving, caregiver's relationship to patient, caregivers' mental, social and functional states, and utilization of health care services and institutionalization.

PROJECT INVESTIGATOR

Dr. Charles W. Given
Department of Family Practice
College of Human Medicine
Michigan State University
East Lansing, MI 48824

PROJECT OFFICER

Kathleen Bond
Behavioral and Social Research
National Institute on Aging
(301) 496-3136

PROJECT PERIOD

5/1/86 - 4/30/89

NATIONAL INSTITUTE OF MENTAL HEALTH PROJECTS

NATIONAL INSTITUTE OF MENTAL HEALTH

The National Institute of Mental Health (NIMH) through the Mental Disorders of the Aging Research Branch funds research awards to increase knowledge and improve research methodology on family stress related to the care of individuals with Alzheimer's Disease (AD) and the development of family care and service delivery models. This research focuses on the generation of systematic information on: the nature, consequences, and interplay of stress associated with caregiving; factors associated with understanding and enhancing family support; the identification, treatment, and management of excess disability in AD patients and strategies to maximize their functional level at all stages of the disease; the prevention of psychopathology and the promotion of mental health among family caregivers; and research on the design and delivery of services providing treatment and clinical interventions for the individuals with AD and for the family members who care for them.

BACKGROUND

AD is a chronic, degenerative, dementing illness of unknown etiology for which there is known cure or intervention to stop the progression of the disease. It is estimated that approximately 2 million older Americans are afflicted with AD and that, as the elderly segment of the U.S. population sharply increases over the next four decades, the number and proportion of afflicted individuals will rise dramatically.

The progressively downward clinical course of AD, with increasing behavioral (wandering, agitation), cognitive (memory, orientations, intellect), emotional (depression), and psychosocial impairment imposes large demands on both formal and informal long-term care networks. Within the formal network, substantial proportions of health and social services to the elderly are used by persons with some form of dementia. AD, which is a major predictor of institutionalization, is often characterized by a lack of thorough assessments, heavy reliance on convenient drug therapies for behavioral problems, poor understanding of proper drug use when medication is indicated, and little attention to nonpharmacological interventions that might help patients and the family. At present, health, social, and personal care services in the community tend to be fragmented, often unresponsive, or unavailable to AD patients and their families. Both institutional and community-based services, when they are available, tend to improve custodial care and do not reflect the state-of-the-art treatment and care for the disorder.

The majority of AD victims reside in a home setting with care provided by an informal caregiver, usually a family member. Continued family caregiving is a major factor in preventing institutionalization and providing needed services and support to the AD victim. Family caregivers, however, experience a variety of psychological, physical, financial, and societal burdens and stress which frequently place the caregivers at risk for developing or aggravating their own health and mental health problems. With prolonged caregiving activities, family units frequently become more vulnerable to dysfunction.

TOPICS OF RESEARCH INTEREST INCLUDE

- o Studies of the nature, consequences, and interplay of stress associated with caregiving on the individual family caretaker, family unit, and the AD patient
 - the nature of risk factors associated with the development of stress-related dysfunction in individual caretakers and family units
 - the nature of short-and long-term physical, psychological, social, and financial consequences of family caretaking, particularly studies on the development or exacerbation of physical (e.g., diabetes, hypertension) or psychological conditions in the caregiver
 - the interaction of family stress, coping strategies, and the management of the AD patient
 - stress and bereavement in the context of the clinical course of AD
- o Research on family support studies, broadly conceived
 - investigations of the nature, type, and extent of family support
 - identification and analysis of individual and family characteristics, interactions, and other variables most amenable to the particular caretaking functions associated with AD, including the identification of factors associated with caregiver satisfaction, positive aspects of caregiving, successful caregiving experiences, and affective coping strategies

- studies to determine the efficacy of the best approaches to teaching behavioral management or other strategies to caregivers and development of valid assessment instruments
- identification and development of strategies to aid the family in the early recognition of symptoms, the decision to seek medical care, and the decision to assume and play a primary caregiver role
- identification of the most effective coping strategies and interventions used by caregivers; and identification of the kinds of information, education, support, and treatment that best reinforce the increased coping abilities of families with AD members
- o Research aimed at the treatment and management of excess disability and the maximizing of AD patients functional level
 - studies to examine factors of the psychosocial and physical environment which shape and maintain positive behaviors in AD patients
 - Development of strategies to maximize the functional level of the AD patient, at all stages of the disease, through the application of mental health treatment modalities
 - development of new approaches for managing behavior most frequently leading to institutionalization
 - identification and reduction of excess disability, including accurate diagnosis and treatment of coexisting physical and psychiatric symptoms
- o Research on the prevention or reduction of psychopathology, symptoms caused by stress, and the promotion of mental health among family caregivers
 - studies on the effectiveness of supportive interventions for the primary caregiver and other family members
 - development of methodologies for assessing specific types of interventions for preventing/moderating stress among family caretakers
- o Research on the design and delivery of services and service systems for AD victims and their caregivers

- identifying an optimal range of community and institutional services relevant to AD in terms of design, staffing, timing of use during the progression of the disorder, mix, and coordination with other services
- studies of the best methods of delivering services such as comprehensive assessment, case (care) management, outpatient treatment, home health care, respite care, adult day care, partial hospitalization, and nursing home care
- strategies for the most effective integration of formal support services provided by health care professionals with informal support intervention provided by family, friends, and neighbors
- application of research in the development of new services for AD patients
- services research demonstrations aimed at developing models for providing a state-of-the-art clinical management, treatment, and care, taking into consideration the context of where treatment and services are provided (e.g., the home, the community, a nursing home)

CARING FOR ELDERS AND MENTAL HEALTH OF FAMILY MEMBERS
NIMH No. R01 MH35360

PROJECT SUMMARY

The first goal of this project is to analyze the extent to which families perceive themselves as effective at providing long-term care for an impaired elder spouse or parent, reported sources of stress related to caregiving, and the impact on family members' health and well-being. Second, the project will examine how family relationships, health and well-being are affected by certain changes.

METHODOLOGY

This is a panel study involving six waves of structured interviews with samples of caregiving and comparison (noncaregiving) families. Purposive sampling was used to obtain family units comprised of: 1) widows living alone and their proximate children; 2) married couples and their proximate children; 3) adult children with functionally intact parents; and 4) older persons with functionally intact spouses.

STATUS

The fifth wave of data collection was completed 3/86 and the sixth is scheduled to begin 9/86. To date there are approximately 120 caregiving, 60 bereaved, 30 nursing home placement, and 20 shared living arrangement families. A report on preliminary findings from T1-T3 has been prepared and analysis of T4 is underway.

INSTRUMENTS/MATERIALS AVAILABLE

Upon request.

PROJECT INVESTIGATOR

Linda Noelker, Ph.D.
Alen Townsend, Ph.D., Co-Principal Investigator and Project Director
500 Hanna Building
1422 Euclid Avenue
Cleveland, Ohio 44115-1989
(216) 621-7201

PROJECT OFFICER

Barry Lebowitz, Ph.D.
NIMH 1895 Parklawn Building
5600 fishers Lane
Rockville, Maryland 20857
(301) 443-1185

PROJECT PERIOD

9-29-80 to 11-30-87

SENILE DEMENTIA PATIENTS: MENTAL HEALTH OF CAREGIVERS
NIMH No. R01 MH37292

PROJECT SUMMARY

This research is investigating the mental health problems associated with caregiving to elderly senile dementia patients and patients without dementia. Caregiver burden, well-being, and quality of daily life of the caregivers and patients are studied as they occur prior to and after institutionalization of the older patient.

METHODOLOGY

Structured interviews, some standardized scales, time budgets and ethnographic participant observation are being used to gather data about 280 people planning to move into nursing homes in Philadelphia area. Each caregiver and patient are interviewed twice in order to ascertain changes associated with institutional admission as compared to the mere passage of time.

STATUS

Half of all initial interviews are completed, with the second interviews completed in 25% of the cases. Data collection to continue into 1987.

INSTRUMENTS/MATERIALS AVAILABLE

Interview protocols - including survey questionnaires and time-budgets for initial interview and the follow-up interview.

PROJECT INVESTIGATOR

M. Powell Lawton, Ph.D.
Philadelphia Geriatric Center
5301 Old York Road
Philadelphia, PA 19141
(215) 455-6162

PROJECT OFFICER

Dr. Barry Lebowitz
Chief, Mental Disorders of the Aging Research Branch
Division of Clinical Research, NIMH
11C-03 Parklawn Building
Rockville, MD 20852
(301) 443-1185

PATIENT CARE, SIBLING RELATIONSHIPS AND MENTAL HEALTH
NIMH NO. R01 MH35352

PROJECT SUMMARY

This research is studying sibling relationships in situations in which a widowed elderly mother needs help and has two or more adult children. The aim of the research is to obtain information on the apportionment of parent care responsibilities within the family and to examine both problems and positive factors in sibling relationships related to caregiving responsibilities for elderly parents.

PROJECT INVESTIGATOR

Elaine M. Brody
Director, Department of Human Services
Philadelphia Geriatric Center
5301 Old York Road
Philadelphia, PA 19141

PROJECT OFFICER

Enid Light
National Institute of Mental Health
Center for Studies for Mental Health of the Aging
(301) 443-1185

PSYCHOSOCIAL COMPONENT OF CLINICAL RESEARCH CENTER
FOR THE STUDY OF SENILE DEMENTIA
NIMH NO. P50 MH40041

PROJECT SUMMARY

The purpose of this study is to longitudinally investigate changes in caregiver function and distress as relatives with Alzheimer's Disease (AD) worsen over time. Thus, the first goal is descriptive: since this program is enrolling patients with early Alzheimer's disease, it affords an opportunity to study the ways in which caregiver problems and coping mechanisms change over time. The second goal is to provide psychotherapeutic treatment for those caregivers diagnosed as clinically depressed.

METHODOLOGY

Patients experiencing symptoms consistent with a diagnosis of early Alzheimer's disease are carefully screened (medically, neurologically, and neuropsychologically). If they appear to meet criteria, they are enrolled in the overall project and are reevaluated at periodic intervals for 5 years. Their family caregivers are similarly interviewed (at the same time the patient is being studied) repeatedly over time. Caregivers who meet DSM-III criteria for a major depressive episode are offered the opportunity to participate in one of several types of short-term psychotherapy for their depression.

STATUS

At present, approximately 75 caregivers have been enrolled in the project and are being interviewed longitudinally. About 35% are clinically depressed. In general, their morale is low, stress is high, and perceived burden is moderate. Pilot data indicate that the majority of those who participate in psychotherapy for depression show improvement in 16-20 sessions, although the more formal randomized study of methods of psychotherapy has not yet begun.

INSTRUMENTS/MATERIALS AVAILABLE

Information about reliability of selected caregiver measures; information about methods of psychotherapy used successfully with caregivers

PROJECT INVESTIGATOR

Jerome Yesavage, M.D.
Stanford University School of Medicine
Department of Psychiatry
Psychosocial component director:
Dolores Gallagher, Ph.D.
Greece/182B
VA Medical Center
3801 Miranda Avenue
Palo Alto, CA 94304
(415) 493-5000 or 858-3989

PROJECT OFFICER

Enid Light
National Institute of Mental Health
Center for Studies for Mental Health of the Aging
(301) 443-1185

CARING FOR DEMENTED SPOUSES: CRISIS VS. ADAPTATION
NIMH NO. R01 MH40480

PROJECT SUMMARY

The goal of the study is to test a model of family stress in which stressors, resources, and perceptions of the adequacy of resources and the demands of stressors predict caregiver stress. Stress is conceptualized both in terms of mental health effects and the ability to continue to provide long term care to an Alzheimer victim in the community.

METHODOLOGY

The design is longitudinal, and involves study of 400 spouses providing care to an Alzheimer victim in the community. Study respondents are interviewed 3 times during the course of one year.

STATUS

150 caregiving spouses have been interviewed once; 40 respondents have been re-interviewed.

INSTRUMENTS/MATERIALS AVAILABLE

Complete interview schedule available by contacting Rachel Pruchno, Principal Investigator, (215) 456-0570. Instrument includes: demographics, caregiving history/behavior and health of spouse, caregiver's health, caregiver tasks and assistance, coping, CES-D, Faces III, consequences of caring, uplifts, Hopkins symptom checklist, life strains, family and social life, expectations/future perceptions, Bradburn Affect Balance, financial information, spouses prior and current personality, MBHI-caregiver personality, interviewer checklist.

PROJECT DIRECTOR

Sheryl Potashnik
Philadelphia Geriatric Center
5301 Old York Road
Philadelphia, PA 19141
(215) 456-0570

PROJECT OFFICER

**Dr. Barry Lebowitz
Chief, Mental Disorders of the Aging Research
Division of Clinical Research, NIMH
11C-03 Parklawn Building
Rockville, MD 20852**

STRESS VULNERABILITY IN ALZHEIMER PATIENT'S FAMILIES
NIMH NO. R01 MH33779

PROJECT SUMMARY

We were chiefly interested in factors related to vulnerability to various kinds of distress in spousal caregivers of Alzheimer's patients. Our main focus was on predictors of depression using social support and cognitive variables as predictors.

METHODOLOGY

Sixty-eight spouses of patients with Alzheimer's Disease were extensively interviewed in four sessions which dealt principally with social supports, attributions and other cognitions about several types of events, and psychodiagnostic evaluations. Thirty-eight of these spouses were reevaluated about ten months after the initial evaluation with a similar battery of measures. Both standardized measures and ones specifically devised for this study were used.

STATUS IN JUNE 1986

Continuing to analyze and write up data. Several papers have been published, are in press, submitted, or in preparation.

INSTRUMENTS/MATERIALS AVAILABLE

Project devised instruments for measuring Alzheimer spouses' attributions and social interaction network.

PROJECT DIRECTOR

Joseph Becker
Department of Psychiatry and Behavioral Sciences RP-10
University of Washington
Seattle, WA 98195
(206) 543-3996

PROJECT OFFICER

Dr. Barry Lebowitz
Chief, Mental Disorders of the Aging Research Branch
Division of Clinical Research, NIMH
11C-03 Parklawn Building
Rockville, MD 20852

THE MENTAL HEALTH OF DEPRESSED AGED AND THEIR CAREGIVERS
NIMH NO. R01 MH39637-01

PROJECT SUMMARY

This study is examining the mental health of caregivers to aged with Major Depressive Disorders and is examining the impact that caregiver coping behavior has on the older patient's depressive illness.

PROJECT INVESTIGATOR

Gregory A. Hinrichsen
Hillside Hospital
(Division of Long Island Jewish Medical Center)
P.O. Box 38
Glen Oaks, New York 11004

PROJECT OFFICER

Enid Light
National Institute of Mental Health
Center for Studies for Mental Health of the Aging
(301) 443-1185

DEPARTMENT OF LABOR ACTIVITIES

The Women's Bureau of the Department of Labor has been concerned for some time about the needs of workers who are providing care to dependents.

Initially, The Women's Bureau was interested in the needs of women employees who had young children and who needed day care services. Then the Bureau also became concerned about the needs of employees who are caring for elderly relatives. A copy of their recent Fact Sheet follows.

Facts on U.S. Working Women



U.S. Department of Labor
Women's Bureau

Fact Sheet No. 86-4
October 1985

CARING FOR ELDERLY FAMILY MEMBERS

Women are both the largest group of providers of eldercare and the largest group of recipients. The majority of older persons in the United States are women. Evidence indicates this will be so into the next century. But with over 55 percent of all working age women either employed or looking for work, there is less time available for the services traditionally provided by wives, mothers, and daughters. This situation will not improve without new approaches to the provision of informal care services. Women are expected to account for two-thirds of the growth of the labor force at least through 1995—in that year, a third of the total labor force will be women ages 25 to 54.

Work and Family. Support for the elderly generally is shared by the family, particularly adult children, and society. The family provides social and psychological support and services, and the community largely provides economic support, through Social Security, but also increasingly through other services.

MARRIED-COUPLE FAMILIES, BY AGE OF MEMBERS AND LABOR FORCE STATUS, MARCH 1984 (Numbers in thousands)

Age of family members	All married-couple families	In Labor Force			
		Husband and wife	Husband only	Wife only	Neither in labor force
Number	50,090	24,333	15,332	2,206	8,219
Percent	100.0	100.0	100.0	100.0	100.0
Under 18 years	50.3	58.4	62.6	26.3	10.0
18 to 64 years	90.1	99.4	96.6	91.2	50.2
65 years and over	18.3	3.6	9.0	36.8	74.1

Source: Current Population Reports, Series P-20, No. 398, Bureau of the Census, U.S. Department of Commerce, March 1984.

Married-couple families with both spouses working represent nearly half (47 percent) of all American families. The dual-earner family now supersedes the "traditional" family that had a single paid worker, usually the man, and a nurturing spouse at home, usually the woman. Also, nearly 17 percent of all families are maintained by women with no spouse present; in more than half of these families, the women are employed.

In March 1984, 18.4 percent of the 62 million United States families had one or more members who were 65 or older. Of more than 50 million married-couple families, some 42 million had either a husband, a wife, or both in the labor force; but only 3.1 million or 7.3 percent of these working families had members 65 years of age or over in the home.

BEST COPY AVAILABLE

Family Support: Who Are the Caregivers? Those caring for functionally impaired elderly family members are predominantly females, with adult daughters providing 29 percent of long-term care and wives providing 23 percent. Three-fourths of caregivers live with the care recipient, and the majority provide assistance 7 days a week, an average of 4 hours a day. About one-fourth of the daughters and one-third of the other female caregivers have competing family obligations.

In 1982 the U.S. Department of Health and Human Services reported that there were approximately 7.6 million informal caregivers providing unpaid assistance to 4.3 million elderly persons who needed assistance with everyday activities. Of these caregivers, some 2.2 million age 14 or older were providing unpaid, informal assistance to 1.2 million noninstitutionalized elderly persons.

SELECTED CAREGIVER CHARACTERISTICS BY RELATIONSHIP OF CAREGIVER
TO DISABLED ELDERLY PERSON, 1982
(Numbers in thousands)

Caregiver characteristics	All caregivers	Relationship of Caregiver to Disabled Elderly Person					
		(Female)			(Male)		
		Spouse	Child	Other	Spouse	Child	Other
Number	2,201	500	637	438	282	186	158
Percent	100.0	22.7	28.9	19.9	12.8	8.5	7.2
Primary caregiver, only	32.8	60.4	23.0	17.5	55.4	10.8	13.1
Lives with disabled person	73.9	99.3	60.6	54.0	98.6	60.6	73.3
Children less than 18 years in home	21.1	5.8	24.2	36.8	5.2	24.5	37.9
Working	30.9	9.9	43.5	32.9	12.3	55.1	45.7
Quit work to become a caregiver	8.9	13.5	11.6	2.9	11.4	5.0	0.8
Not working for other reasons	59.7	75.2	44.7	64.2	76.3	39.9	53.5

Notes: "Other" includes sons or daughters-in-law, siblings, grandchildren, other relatives and nonrelatives. "Disabled" is defined as being limited in one or more activities of daily living, e.g., eating, bathing, dressing, getting in and out of bed or chair, getting around inside.

Source: 1982 National Long Term Care Survey/Survey of Caregivers, U.S. Department of Health and Human Services.

Competing Demands. Work conflicts with caregiving responsibilities. While less than 10 percent of the 2.2 million persons providing care to functionally impaired elderly relatives quit their jobs to care for someone, a sizable proportion of working female and male caregivers have had to rearrange schedules (29 percent), reduce work hours (21 percent), and/or take time off without pay (19 percent) to fulfill caregiver obligations.

Because of longer life expectancies, rising median ages of the population and labor force, and delayed childbearing, an increasing proportion of women will be providing care to children under the age of 18 as well as elderly relatives. These demographic trends and the projected increases in labor force participation rates among all women suggest that in the future work and family obligations may conflict with caregiving responsibilities to a greater extent than today.

Of all the caregivers in 1982, 79.8 percent provided unpaid assistance 7 days per week. Three-fourths of daughters and 71 percent of sons devoted part of each day to caregiving activities. Only 16 percent of all primary caregivers with no assistance were employed; about 31 percent of those who had unpaid help were employed and 27 percent who had a combination of paid and unpaid help were working.

EMPLOYMENT STATUS OF CAREGIVERS BY LEVEL OF ASSISTANCE, 1982
(Numbers in thousands)

Status	Primary caregiver only	Primary caregiver with informal help	Primary caregiver with informal/formal help	Secondary caregiver
Number	722	630	212	637
Percent	100.0	100.0	100.0	100.0
Working	15.0	30.8	27.2	49.4
Not working	73.2	58.7	64.6	42.5
Never worked	10.6	9.5	8.2	8.1

Source: 1982 National Long Term Care Survey/Survey of Caregivers, U.S. Department of Health and Human Services.

WORK ARRANGEMENTS TO ACCOMMODATE CAREGIVING, 1982

Arrangements	All Persons
Number	1,023,000
Percent	100.0
Worked fewer hours	21.0
Rearranged schedule	29.4
Took time off without pay	18.6

Source: 1982 National Long Term Care Survey/
Survey of Caregivers, U.S. Department of Health
and Human Services.

Women were more likely than men to arrange their schedules to care for elderly relatives. Wives rearranged their schedules more often than husbands; daughters more often than sons took each of the three options to reduce work-family conflict.

Childcare and Eldercare Needs. Some family caregivers are both parents of dependent children and care providers for elderly family members. In 1982, almost one-fifth of all caregivers, one-fourth of caregiving children and one-third of other caregivers reported having children under 18 years of age in their households.

The burden for workers responsible for both children and elderly relatives, however, is expected to be especially great in the years of the next century when the baby boom cohort largely constitute the members of the elderly population. Many persons then ages 45 to 49 will have to support both an aged parent or parents, often over 70 years, and children of college age, or younger.

Care of Those Living Alone. Many elderly persons do not live in the same household as their caregivers. According to the U.S. Department of Health and Human Services National Health Interview Survey Supplement on Aging, about 31 percent of all persons age 65 and over, or 8 million people, were living alone in 1984. On average, they were older than those who lived with others, averaging 75.2 years. Eighty percent were women, mostly widows. While 29 percent had no living children, half of those who had children lived close enough to them to get help within a matter of minutes. Nearly one-fourth (23 percent) had daily contact with their children. Almost 70 percent relied upon their families to take care of them as needed.

Conclusion. Stresses of competing demands of work and family, including responsibility for care of elderly relatives, have increasingly come to the attention of employers and policymakers. Alleviation of distractions

and concerns of workers in these situations has been provided by some employers through a variety of alternative work arrangements including flexible leave and work times, and providing information and referral assistance for care services. For additional information on alternative work scheduling, write to the Women's Bureau for a free copy of "Alternative Work Patterns," Fact Sheet No. 86-3. Information on services for older people is available from local area agencies on aging. The telephone number of the area agency on aging may be found in the telephone book under "Aging" or "Senior Citizens."

Resources. "Caregivers of the Frail Elderly: A National Profile," by Robyn Stone, M.D., P.H. and others, 1986, National Center for Health Services Research and Health Care Technology Assessment, U.S. Department of Health and Human Services. "Aging in the Eighties, Age 65 Years and Over and Living Alone: Contacts with Family, Friends, and Neighbors," *Advancedata*, Number 116, May 9, 1986, National Center for Health Statistics. Demographic and Socioeconomic Aspects of Aging in the United States, Current Population Reports, Special Studies, Series P-23, No. 138, August 1984, Bureau of the Census, U.S. Department of Commerce. Household and Family Characteristics, March 1984, Current Population Reports, Series P-20, No. 398, April 1985, Bureau of the Census, U.S. Department of Commerce.

**U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES**
Washington, D.C. 20201

OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE \$300

Postage and Fees Paid
U.S. DEPARTMENT OF H.H.S.
HHS-393

